Help-Seeking Among Mothers with Postpartum Obsessive Compulsive Disorder

A Phenomenological Exploration

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THESIS

Submitted as partial fulfillment of the requirements
For the degree of Doctor of Philosophy in Social Work
In the Graduate College of the
University of Illinois Chicago, 2021

Chicago, Illinois

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DEDICATION PAGE

This dissertation is dedicated to all of the women who have endured postpartum OCD, and

especially to those who are still suffering in silence.

ACKNOWLEDGEMENTS

First and foremost, all gratitude and glory to God for equipping me with the inspiration, support, and human and material resources essential to the successful completion of the journey that was this dissertation project. I know that through you, all things are indeed possible!

I would like to thank my incredible dissertation committee, who have poured time and energy into this project and my learning and growth overall. To Amy Watson, thank you for all your support, encouragement, and sharing of knowledge and resources. I appreciate your belief in my abilities, and your guidance through the development of this project, from vague idea to successful completion. Dr. Chang-ming Hsieh: Thank you for your recognition and encouragement of my abilities, and your helpful responsiveness to all my inquires and issues throughout my entire tenure in the doctoral program. To Dr. James Swartz, thank you for having high expectations for me and never allowing me settle for "good enough". Thank you for investing in my scholarly development, and for always being there to help me work through obstacles along the way. To Dr. Christopher Mitchell, your enthusiasm for teaching and lifelong learning has been inspiring. Thank you for helping to "teach me how to teach", and for your thoughtful feedback. Dr. Sarah Abboud, thank you for encouraging my interest in phenomenological research methods, and sharing the well-spring of knowledge you have in this area. Your feedback and mentorship has been so valuable to my development as a qualitative researcher. To Dr. Jack Lu: thank you for spending countless hours in the trenches with me on this project, and so freely sharing your knowledge and ideas. Thank you for the depth of emotional support you have provided during those times I was growing fatigued and my confidence was waning; thank you for always being there to listen and gently guide.

To my parents, Geri and Larry Labash. Thank you for the tremendous financial, emotional, and practical support you have provided throughout my time in the doctoral program (and throughout my entire life!). I would never have gotten here had it not been for your encouragement and unwavering belief in me. To my husband, Jimmy: thank you for always

being there for me throughout the process of writing this dissertation. I'm still not sure how we managed to get through this incredibly stressful (allbeit joyful) time in our lives. You are my anchor and I love you more than words can express. To my children, Lena and James. Being your mother has been the most beautiful, rewarding and challenging experience of my life. Thank you for being such an important part of my "why". You are at the core of every decision I make, every effort I decide to undertake.

Finally, thank you to the brave, amazing mothers who so candidly shared their experiences with me, for your willingness to re-explore a painful time in your lives in order to shed light on postpartum OCD in the hopes of helping others. I have learned so much from each of you. Thank you for entrusting me with your stories….they continue to inspire me moving forward.

TABLE OF CONTENTS

SUMMARY

While the significance of maternal mental health and illness is increasingly being recognized by clinicians and scholars, perinatal mental health problems remain under-identified, and subsequently under-treated. Postpartum Obsessive Compulsive Disorder (ppOCD) is a maternal mental health disorder characterized by persistent, unwanted intrusive thoughts, and associated behavioral compulsions. Left untreated, ppOCD can lead to significant psychological distress in the mother, as well as bring about deleterious consequences within the family unit. Equally problematic, ppOCD can be an especially difficult maternal mental health condition to identify given prevalent misconceptions and misunderstandings about OCD, and particularly its presentation in perinatal women. Presently, research on women's lived experiences with having and seeking help for ppOCD is severely lacking.

To address this gap, I utilized a qualitative interpretive phenomenological research design to obtain a deeper understanding of the lived experiences of six mothers who had sought help for ppOCD. This study explored two overarching phenomenological questions: 1) What is it like to experience ppOCD? 2) What is it like to seek help for ppOCD?

Data were gathered via unstructured, in-depth interviews as well as member-checking follow-up phone calls. Using a phenomenological-hermeneutic analytic approach based on Ricoeur's Interpretation Theory and informed by the Network Episode Model, data were analyzed and initial impressions presented to participants as "found poems" using verbatim words and phrases from each participant's interview transcript. Participants' reactions to found poems, as well as emerging individual and collective themes were discussed during the follow-up phone calls.

Four overarching experiential themes were uncovered during the analysis process. Findings indicated that mothers experienced great emotional distress during the onset of their ppOCD-related intrusive thoughts and associated symptoms. At symptom onset, mothers had no existing knowledge about ppOCD, and struggled to make sense of their postpartum

SUMMARY

experiences. Feelings of shame about the content of ppOCD intrusive thoughts, as well as

perceived public- and self-stigma, impeded their help-seeking process. Mothers perceived the

mental health referrals given by hospital systems to be largely inappropriate for their needs. In

some cases, early encounters with mental health providers unfamiliar with ppOCD resulted in

initial misdiagnosis and further stigmatization. Alternatively, a self-directed process of

knowledge and resource seeking via independent internet research and social networking

promoted feelings of personal empowerment, facilitating professional help-seeking. Obtaining

an accurate diagnosis, working with a mental health practitioner who "understood" ppOCD, and

having a strong social support network all facilitated having a greater understanding of their

symptoms, decreased psychological distress, and promoted resilience.

I.   INTRODUCTION

In contemporary society, pregnancy and the birth of a child are typically regarded as joyous life events. However, while the perinatal period can indeed be an exciting time, it is also a space wherein many women experience significant mental health challenges. Maternal mental illness is widespread, and associated with many adverse outcomes for mothers, families, and families. Over the past decade, research on perinatal mental health disorders and associated health outcomes has led to the development and implementation of new programs and interventions aimed at improving the identification and treatment of perinatal mood and anxiety disorders (PMADs). To date, much of the existing research literature on PMADs is focused on the identification and treatment of postpartum depression, with a relatively small but growing body of research is dedicated to peripartum anxiety disorders and Post-traumatic stress disorder (Davis et al. 2018; Khan, 2015). While these developments are promising, as a whole, clinically significant maternal mental health problems are still believed to be under-identified and thus under-treated (Khan, 2015). This is especially true for certain types of perinatal mental disorders, such as postpartum Obsessive Compulsive Disorder (ppOCD).

PPOCD is a mental disorder that emerges during pregnancy or after birth (postpartum). Currently, it is regarded as "the most misunderstood and misdiagnosed" perinatal mental health condition by Postpartum Support International, the largest support and advocacy organization for perinatal mental health (Postpartum Support International [PSI], 2021). Left unidentified and untreated, the psychological distress of ppOCD may significantly impair functioning in multiple life areas (Blakey & Abramowtiz, 2017; Speisman et al., 2011; Jacob & Storch, 2013). While behavioral health treatment has demonstrated clinical efficacy and effectiveness for the treatment of OCD during the postpartum period, women experiencing ppOCD face considerable barriers to diagnosis and treatment (Blakey & Abramowitz, 2017; Frías et al., 2015; Speisman et al., 2011; Zambaldi et al., 2009).

PPOCD is associated with public stigma as well as self-stigmatizing attitudes and beliefs, negatively influencing help-seeking (Frías et al., 2015; Speisman et al., 2011; Tareen & Tareen, 2015). Limited general and clinical awareness of ppOCD, exemplified by the absence of screening protocols, health provider training, and prenatal education about the illness, may exacerbate stigma, contributing to reduced help-seeking behaviors (Jacob & Storch, 2013; Frías et al., 2015). To date, much of the limited literature on ppOCD has emerged from the Medical field and has mainly focused on symptomatology, risk factors, etiology, and other factors affecting clinical classification (e.g., Sichel et al., 1993). Virtually no studies focus on mothers' *lived experiences* with ppOCD. To address this gap, this dissertation research utilized a qualitative, interpretive phenomenological research design to explore, describe, and collaboratively interpret mothers' ppOCD experiences, with special attention to their experiences with help-seeking.

A. Background, Significance, and Rationale of the Study

Maternal mental illness is a widespread public health concern, adversely affecting mothers, children, and families (Howard et al., 2014; Khan, 2015; Millet et al, 2017). Internationally, approximately 15-20 percent of childbearing women are affected by some type of mental illness during pregnancy or within the first year after birth (Howard et al., 2014; Khan, 2015). Most women experience common mental health problems such as depressive and anxiety disorders, while fewer experience conditions such as bipolar disorder, post-traumatic stress disorder, and psychosis (Davis et al., 2018; Howard et al., 2014; Khan, 2015). Untreated mental illness of any type during the perinatal period is associated with deleterious outcomes for mother, child, and family. For example, perinatal mental illness has been shown to negatively affect mother-child attachment and bonding (Challacombe et al. 2016), negatively impact the cognitive, social, and physical development of infants (Sutter-Dallay et al., 2011), and generate considerable strain on interpersonal relationships (Asselman et al., 2016). Notably, suicide is a

leading cause of maternal death in high income countries (Lindahl et al., 2014). While advocacy and research efforts have raised awareness of some types of perinatal mental illness, such as postpartum depression, maternal mental illnesses remain stigmatized, under-identified, and under-treated (Davis et al,, 2018; Fonseca et al., 2018).

Although women with perinatal mental illness experience significant psychological distress, rates of mental health care utilization and help seeking are low (Fonseca et al., 2018; Goodman & Tyer-Viola, 2010; O'Mahen & Flynn, 2008). Despite the availability of effective medical and psychological treatment, only 10-20% of women actively seek help for their mental health problems during the peripartum period (Dennis & Chung-Lee, 2006; O'Mahen & Flynn, 2008). Low rates of treatment seeking are especially concerning given that women with these illnesses are often not identified by the health care system, despite frequent contact with healthcare providers throughout pregnancy and the first few weeks postpartum. Research has found that women with clinically significant peripartum mental health disorders are identified by healthcare providers at a rate of only 10% (O'Mahen & Flynn, 2008) to 50 percent (Khan, 2015). Women experiencing postpartum OCD, in particular, may be at especially high risk for under-detection, and consequently, under-utilization of treatment (Frías et al., 2015; Speisman et al., 2011; Tareen & Tareen, 2015).

Obsessive Compulsive Disorder (OCD) is characterized by "intrusive, anxiety-provoking thoughts, impulses, or images and/or the performance of ritualistic or compulsive behaviors in an effort to reduce anxiety" (Jacob & Storch, 2013, p.64). Among the general population, OCD occurs less commonly than other psychiatric disorders such as Major Depression and Generalized Anxiety Disorder, but may cause greater functional and role impairment (Ruscio et al., 2010). According to results from the National Comorbidity Study-Revised (NCS-R), lifetime prevalence and past year prevalence of OCD is 2.3 percent, and 1.2 percent, respectively (Ruscio et al., 2010). Although OCD is not especially common among the general public, the condition has a significant negative impact on public health, with marked functional impairment

negatively impacting social functioning, family, and work/employment, and is considered to be a leading cause of worldwide disability (Robinson et al., 2017; Ruscio et al, 2010; Speisman et al., 2011; Steinberg & Wetterneck, 2017). OCD typically runs a persistent, chronic course, and is associated with low levels of help-seeking, despite high levels of distress and impairment (Belloch et al., 2009; Robinson et al., 2017; Ruscio et al., 2010). Among those who do seek help, treatment-seeking is often extremely delayed, with an average time of 8 years from onset of symptoms to receiving a formal diagnosis (Wang et al., 2005).

In recent years, the postpartum period has been recognized as an especially vulnerable time for the onset, re-emergence, or exacerbation of OCD symptoms (Blakey & Abramowitz, 2017; Miller et al., 2013). The term "Postpartum OCD" (referred to as "Perinatal OCD" when occurring during pregnancy) may be defined as:

The rapid onset of OCD or worsening of existing OCD during pregnancy or the postpartum period heralded with obsessions involving fears of contamination, illness, causing harm, intentional or accidental, and anxiety about losing the baby (Tareen & Tareen, 2015, p.220).

While not currently recognized as a separate OCD subtype, ppOCD is associated with a distinct symptomatology and clinical course (Blakey & Abramowtiz, 2017; McGuiness et al., 2011; Speisman et al., 2011). Specifically, the content of the obsessive intrusive thoughts tend to be highly specific to the infant's safety. In the majority of cases, symptoms include persistent unwanted thoughts or images of intentionally harming one's child through physical or sexual aggression, but may also include thoughts and images of accidental harm or contamination (Frías et al.. 2015; Speisman et al., 2011; Zambaldi et al., 2009).

The need for increased research on virtually all aspects of ppOCD has been well documented (Davis et al., 2018; Howard et al., 2014; Jacob & Storch, 2013; Speisman et al., 2011). Research suggests that, unlike other perinatal mood and anxiety disorders which occur at rates similar to those observed in the general population (Vesga-Lopez, 2008), the perinatal period reflects a time of significantly *increased* vulnerability for the development of OCD (Blakey

& Abramowitz, 2017; Guglielmi et al., 2014; Speisman et al., 2011; Tareen & Tareen, 2015; Zambaldi et al., 2009). Few studies have assessed the prevalence rates of clinical OCD among new mothers, and of those that have, estimates from nonclinical samples vary widely, ranging from 1-3 percent (Abramowitz, 2006) to 9 percent (Zambaldi et al., 2009).

Presently, the prevalence rate of ppOCD is estimated at approximately 5 percent, compared with 1-3 percent for the general United States population (Miller et al., 2013; Ruscio et al., 2010). Further, in retrospective studies examining stressful life events in relation to the onset or exacerbation of OCD symptoms, pregnancy and the postpartum period has consistently been identified as a major trigger for the emergence of symptoms (Ugoz, et al., 2007; Abramowitz et al., 2003; Blakey & Abramowitz, 2017; Speisman et al., 2011).

In addition to great psychological distress to the mother, maternal OCD is associated with behavior which may be detrimental to mother-child bonding as well as general infant care (Challocombe et al., 2016; Jacob & Storch, 2013; Zambaldi et al., 2009). For example, mothers who experience aggressive intrusions (harm OCD) often avoid or greatly minimize interactions with their infants due to fear of acting on their intrusive thoughts (Jacob & Storch, 2013; Tareen & Tareen, 2015). In one study, mothers with ppOCD were found to have less confidence, lower rates of breastfeeding, less sensitivity and lower levels of enjoyment across parenting tasks, higher levels of marital distress, and less social support when compared with their healthy peers (Challacombe et al., 2016).

Women experiencing any type of mental illness during the perinatal period experience several barriers to receiving mental health treatment. In a large study that analyzed survey data collected from British primary care doctors, women, and family members, "low identification of need" was found to be the overarching reason for low rates of mental health care access during the perinatal period. The study found inconsistency and discontinuity in the health care system to be among the most salient barriers. For example, providers, women, and families all identified great variation in the knowledge, awareness, and skill of general practitioners in identifying and

addressing symptoms of mental illness among mothers (Khan, 2015). This finding was applicable across practice locations as well as between providers at the same practice location (Khan, 2015). Among women whose mental health issue was identified, poor follow-up and progress tracking impeded further symptom disclosure and mental health treatment access (Khan, 2015).

While screening for postpartum depression is now common in most health care settings that provide perinatal health services, routine health care rarely includes screening for other perinatal mental health concerns such as perinatal anxiety disorders or OCD (Misri et al., 2015; O'Mahen & Flynn, 2008). Although these disorders may (and often do) co-occur with depressive disorders, the screening instruments used for detecting postpartum depression are not designed to identify potential comorbid disorders, such as postpartum OCD (Misri & Swift, 2015).

Perinatal mental health disorders are diagnosed according to the same DSM-5 criteria that is used to diagnosis mental health conditions that emerge during any other period throughout the life cycle. However, the most recent Diagnostic and Statistical Manual for Mental Disorders, (DSM-5) only includes the specifier "with peripartum onset" in relation to mood disorders and psychosis, and not anxiety disorders nor OCD specifically (American Psychiatric Association, 2013; Davis et al., 2018). This may further limit health providers' knowledge of the myriad mental health conditions other than peripartum depression that may arise during the perinatal period. As some degree of anxiety, including the occasional experience of intrusive thoughts, is regarded as "normal" during the peripartum period, it may be difficult for untrained providers to distinguish normative worrying (i.e. concerns about the infants safety and well-being) from pathological anxiety indicative of a more serious disorder, such as ppOCD (Jacob & Storch, 2013).

As symptoms associated with ppOCD tend to differ from symptoms of OCD that occur at other times throughout the life cycle, and bear certain similarities to both postpartum depression and postpartum psychosis, ppOCD is often missed altogether or misdiagnosed for another

condition that is more widely known (Speisman et al., 2011). Further complicating the issue, postpartum OCD is highly comorbid with postpartum depression, and certain OCD symptoms may be interpreted as depressive symptoms or psychosis among providers who do not have specialized training in recognizing ppOCD (Speisman et al., 2011). Comorbid ppOCD and postpartum depression is associated with an especially severe clinical presentation and course and requires the treatment of both conditions (Speisman et al., 2011). Mothers who acknowledge their depressive symptoms but neglect to report their OCD symptoms may receive incomplete or inappropriate treatment for their comorbid OCD. Research suggests that symptoms of OCD intrusive thoughts are commonly not reported at all, or only the most mild symptoms are disclosed (Blakey & Abramowitz, 2017; Frias et al., 2015). As a result, individuals experiencing ppOCD may be at especially high risk for under-identification of their illness, due in part to poor recognition of the illness among both affected persons and providers, as well as increased stigma due to the nature of the illness (Howard et al., 2014; Jacob & Storch, 2013; Misri et al., 2015).

Research suggests that women with perinatal mental health problems experience both public stigma and self-stigma (Davis et al. 2018, Fonseca et al., 2015; Edwards & Timmons, 2005; Howard, 2014; Khan, 2015; Millet et al., 2017 Pinto-Foltz & Logsdon, 2008). While previous studies have explored the concept of stigma in relation to postpartum depression (e.g. Fonseca et al., 2018; Mickelson et al., 2017; Pinto-Foltz & Logsdon, 2008), no existing studies have focused on the experience of stigma and self-stigma among mothers with ppOCD specifically. However, stigma and self-stigma is a well-documented psychological barrier to care across the OCD literature (Fennell & Liberato, 2007; Mcarty et al., 2017; Murphy & Perera-Delcourt, 2014; Robinson et al., 2017; Steinberg & Wetterneck, 2017).

Among OCD sufferers, individuals who experience intrusive thoughts of an aggressive or taboo nature (as is common in ppOCD) may be more likely to avoid symptom disclosure and delay treatment-seeking due to embarrassment, shame, and fear of stigmatization (Fennell &

Liberato, 2007; McCarty et al., 2017; Moulding et al., 2014; Steinberg & Wetterneck, 2017). Individuals experiencing aggressive intrusive thoughts "attempt to purge them from their minds or to suppress them, often through avoidant control strategies, such as by using magical or superstitious compulsive behaviors, or thought control strategies" (Moulding et al., 2014, p.163). In one study, which found a 39 month average delay in treatment-seeking among individuals with OCD, fear of stigma and fear of the meaning of thought intrusions were identified as a major reasons for delays in consultation (Belloch et al., 2008). However, another study found that the experience of aggressive thought intrusions promoted *more* timely treatment seeking due to fear of acting on the aggressive thought and causing harm to another (Robinson et al., 2017).

In the case of perinatal mental illness, fears of having children removed if symptoms of peripartum psychological distress are disclosed are well-documented (Byatt et al., 2014; Davis et al., 2018; Edwards & Timmons, 2005; Khan, 2015; Millet et al., 2017). For this reason, women who experience intrusive thoughts and images of violence toward their children may be especially fearful to disclose their symptoms to both providers and social supports (Frías et al., 2015; Howard et al., 2014; Jacob & Storch, 2013). Frías et al. (2015) state, "mothers with obsessions related to their children (e.g. aggressive intrusions) usually hide or minimize these symptoms for fear of being stigmatized, which results in less treatment demands (underdiagnosis) and in a higher risk of the disorder to become chronic" (p.1695). If intrusive thoughts are kept secret due to fear or shame, it is difficult or impossible for accurate diagnostic procedures to ensue.

In a qualitative study that explored the effects of labeling on stigma among individuals with OCD, Fennell & Liberato (2007) found mixed effects among participants—some people reported that receiving a diagnosis of OCD reduced stigma and others felt that the diagnostic label increased stigma. The reactions from social network members (i.e. friends, family, coworkers, health providers) following disclosure of diagnosis and treatment history shaped how and to whom respondents disclosed their diagnostic labels and symptoms in the future (Fennell & Liberato, 2007). When treatment for OCD is actively sought, the initial reactions of healthcare providers are

highly influential in facilitating or hindering additional treatment seeking and utilization (Robinson et al., 2017). Unfortunately, some research has found stigmatizing attitudes toward individuals with OCD, especially toward those experiencing violent or sexual intrusive thoughts (Steinberg & Wetterneck, 2017). Similarly, mothers experiencing perinatal mental illness have reported the perception of stigma from providers as a significant barrier to further help-seeking (Byatt et al., 2014; Khan, 2015; Millet et al., 2017).

Self-stigma refers to the acceptance of public stigma and the application of associated attitudes and perceptions toward oneself (Corrigan & Watson, 2002). Among those affected by OCD, the experience of aggressive intrusive thoughts may lead to the experience of self-stigmatizing attitudes, and the development of a "feared self" where the individual regards themself as "bad, immoral, or insane" based upon the content of the intrusive thoughts (Moulding et al., 2014). Research suggests that this process may begin well before a diagnosis of OCD is made, at the point that individuals begin to subjectively identify their thoughts and behaviors as abnormal in relation to their social context (Fennell & Liberato, 2007). Considering the ego-dystonic nature of aggressive intrusive thoughts, individuals affected by OCD "may face a struggle distinguishing their 'real' thoughts from the 'OCD' thoughts...they wonder if the thoughts indicate some deep-felt urge, if they will act on their thoughts" (Fennell & Liberato, 2007, p.315). Not surprisingly, women with postpartum OCD who experience intrusive thoughts about harming their children often develop exceedingly negative appraisals about themselves as people or mothers (Speisman et al., 2011; Tareen & Tareen, 2015).

To improve rates of identification and treatment for ppOCD, health providers should have an understanding of maternal mental illnesses, their various manifestations, and treatment indications. Social workers in general hospital or specialty maternal/child health settings are often responsible for administering and/or following-up on compulsory maternal mental health screenings, and providing referrals for further care. Social workers working in health care, especially, should have a thorough understanding of maternal health and illness. Further, social

workers (and other health providers) should have knowledge about the multitude of systemic, cognitive, and attitudinal barriers to care—and how informal and formal support networks may promote or deter help-seeking. These factors should be considered in the process of treatment planning, referral, and linkage for ppOCD.

B. **Theoretical Framework: The Network Episode Model**

The Network Episode Model (NEM; Pescosolido, 1991; Pescosolido et al., 2013) is one lens through which I have considered and interpreted the study data. Applied as a sensitizing framework, the NEM and the associated concept of the illness career allowed me to appreciate a more nuanced understanding of the way in which interpersonal relationships and interactions influenced participants' beliefs and behaviors throughout their journey with ppOCD. The original NEM was developed in response to other models of health service utilization that assumed involvement in health care was the product of individual, rational choice (e.g. Andersen's Sociobehavioral Model; Andersen, 1968, 1995) or, in the case of mental health specifically, legal coercion (e.g. Monahan et al., 1996). The NEM, instead, conceptualizes help-seeking as an interactive, dynamic process that is situated within the individual's particular social context. In this model, the structural, functional, and cultural characteristics of social network ties, and the interactions between them, are viewed as the key to understanding behaviors of health and illness, including help-seeking decisions and degree of treatment involvement (Pescosolido,1991; 1992; Pescosolido et al., 2013). The NEM considers the influence of social interactions on actions and experiences such as recognizing health issues, making contact with health care systems, engaging in treatment, and adhering to treatment recommendations throughout an episode of illness (Pescosolido, 1991).

Various iterations of the NEM (i.e., NEM; NEM II; NEM III; Pescosolido, 1991; 2011; Pescosolido et al., 2013) have been applied as a theoretical framework in several qualitative studies exploring help-seeking behaviors and attitudes. The NEM and the associated concept of

the illness career have been considered to better understand mental health related help-seeking and treatment utilization among diverse populations such as adolescents with ADHD (Williamson et al., 2009), juvenile offenders (Watson, et al., 2009), adults with self-injurious behaviors (Long et al., 2015), and older adults with mental health problems (Beatie et al, 2020). To my knowledge, the model has not been applied with OCD- or perinatal-specific populations.

Due to the highly stigmatizing and complex nature of ppOCD, it is important to gain awareness of the various influences on help-seeking for this specific maternal mental health condition. Given the low rates of formal help-seeking among individuals with perinatal mental illness *and* individuals with OCD, it is important to understand how women who sought treatment for ppOCD experienced the process of help-seeking. The NEM (Pescosolido, 1991) was selected as a sensitizing framework for this dissertation research given its' recognition of the complex nature of help-seeking for mental health conditions, and the way in which social relationships and interactions may influence an individual's trajectory through the health system. Consistent with a phenomenological research approach, the NEM recognizes the importance of lived experience and social context, from the perspectives of individuals with mental illness, in understanding the complex process of help-seeking for mental illness (Pescosolido et al., 1998; Pescosolido et al., 2013).

C. <u>Qualitative Methodological Approach: Interpretive Phenomenology</u>

A qualitative, interpretive phenomenological research approach was selected for this dissertation research with careful intention. It is a methodological approach that allows for a deep exploration and understanding of the lived experiences of individuals who have experienced a common phenomenon, with an emphasis on the meanings that they attribute to those experiences (Moustakas, 1994). In the health and social sciences, phenomenological methods are indicated when information is needed to develop a more in-depth understanding of a particular lived experience, such as having an illness, in order to more fully understand the

illness and how individuals may experience it (van Manen, 1997). As such, phenomenological inquiry can provide key insight useful for the development and implementation of health care practice and policy (Creswell & Poth, 2018).

In the case of mental illness, specifically, phenomenological inquiry challenges the medicalization of psychiatry by giving voice to the subjective experience of the individual who is experiencing the illness, instead of relying solely on observable behavior to conceptualize and classify mental disorders (Aho, 2008). Qualitative research is useful to "empower individuals to share their stories [and] hear their voices" (Creswell & Poth, 2018, p.44). A primary aim of social work is not only to assuage suffering, but to identify strengths and support wellness at all levels (Brekke, 2014). By empowering women who have experienced postpartum OCD to tell their stories, to be the authors of their own experience, this dissertation research supports the strengths-finding mission of social work. This dissertation study has practical relevance for social workers working in emergency care, as well as maternal and child health.

D. Research Questions

In this dissertation study, I utilize an interpretive phenomenological qualitative research methodology to explore, describe, and collaboratively interpret the lived experiences of six mothers who have lived with ppOCD. The primary aim of the proposed study is to gain a deeper understanding of the lived experience of ppOCD by exploring two overarching and interconnected phenomenological research questions:

1) What is it like to experience ppOCD?
2) What is it like to seek help for ppOCD?

II.   REVIEW OF THE LITERATURE

Obsessive Compulsive Disorder (OCD) is a debilitating condition that is associated with high levels of psychological distress, as well as functional and role impairment (American Psychiatric Association, [APA] 2013). In recent years, increased attention has been placed on the manifestation of Obsessive Compulsive Disorder during the perinatal period, a time that has been associated with increased vulnerability for the development or exacerbation of OCD symptoms (APA, 2013; Sichel et al.,1993; Zambaldi et al., 2009). However, much of the existing literature on postpartum OCD has emerged from the medical field and focused on clinical presentation and etiology (e.g. Sichel et al., 1993; Jacob & Storch, 2013), with virtually no research on the lived experiences of women with postpartum OCD. While research on OCD during the postpartum period is extremely limited, studies find consistently low rates of help-seeking among both individuals with OCD and among individuals with perinatal mental illness.

The following review will first provide an overview on OCD and Postpartum OCD, to familiarize the reader with the clinical presentation and common issues associated with OCD. To contextualize the study, the major tenets of the NEM and its use with populations experiencing mental illness will be discussed. Because empirical literature on the experiences of help-seeking among women with postpartum OCD is scant, the following sections will present the literature on various concepts related to the help-seeking experiences of a) women experiencing peripartum mental illness, and b) individuals with OCD.

A. **Obsessive Compulsive Disorder (OCD)**
1. **Overview**

OCD is characterized by the experience of obsessions, defined as "recurrent, persistent, thoughts, impulses, or images that are experienced as intrusive and cause great anxiety" (Abramowitz et al., 2009, p. 491). Most, but not all, individuals with OCD also engage in compulsive behaviors in direct response to the obsessions. Compulsions are mental actions or repetitive behaviors that are performed in an attempt to suppress the intrusive thoughts or

prevent negative events. Prior to 2013, OCD was classified as an Anxiety Disorder by the American Psychiatric Association. While persistent, often severe, anxiety is a key experience with OCD, several features distinguish OCD from anxiety disorders such as generalized anxiety disorder (GAD) and Panic Disorder (PD).

OCD is considered to be a heterogeneous condition, with a multitude of symptom presentations, although symptoms tend to cluster into categories. The *Diagnostic and Statistical Manual of Mental Disorders* (5th ed; DSM-5; American Psychiatric Association [APA], 2013) recognizes four broad symptom dimensions including: 1) Cleaning, consisting of obsessions involving contamination and compulsions involving excessive cleaning; 2) Symmetry, consisting of obsessions related to symmetry and compulsions involving counting, ordering, and repeating; 3) Forbidden or taboo thoughts, involving aggressive, sexual, or religious thoughts and compulsions; and 4) Harm, involving fears of causing harm to oneself or another and compulsions involving excessive checking (APA, 2013). A diagnosis of OCD is typically made by clinical interview and requires that the individual is consumed by the obsessions and/or compulsions in excess on one hour per day, and/or the presence of significant psychological distress or impairment in social, occupational, or other pertinent domains of functioning (APA, 2013). Importantly, clinical OCD is distinguished from excessive amounts of normative "worrying" about everyday events. With OCD, great efforts are made to suppress or control the intrusive thoughts (i.e., obsessions), typically through the acting out of behavioral compulsions or mental rituals (APA, 2013; Abramowitz et al., 2009).

2. <u>The Cognitive Model</u>

Cognitive Models of OCD posit that OCD symptoms are caused or worsened by the presence of "normal" intrusive thoughts that have been misappraised (Salkovskis, 1985). Occasional intrusive thoughts are common among people who do not have OCD (Young et al., 2021), and very common to new parents, with occasional intrusive thoughts involving harm to

the infant found to occur among 49-69 percent of new parents (Fairbrother & Abramowitz, 2007). While individuals who have occasional intrusive thoughts may be initially emotionally upset in response to the thought content, most people dismiss them as random and meaningless. Individuals with OCD, however, may interpret "normal" intrusive thoughts as "unacceptable", and experience great difficulty dismissing them as random (Calkins et al., 2013; Salkovskis, 1985). Intrusive thoughts lead to anxiety when they are perceived to have a deeper meaning—that the unwanted thought represents a deep-seated unconscious desire, or that having the thought will increase the likelihood that it will occur in reality (Salkovskis, 1985). Individuals with OCD often believe that having a thought (e.g. harming a loved one) means that it will actually occur, and/or that having the thought is morally equivalent to it actually occurring (Calkins et al., 2013). As such, attempts are made to suppress or "undo" the distressing thoughts through behavioral compulsions. While compulsions may involve superstitious, magical thinking, the individual with OCD recognizes that the obsessions emerge from their own mind and have not been inserted by another entity, as in some presentations of psychosis (Zambaldi et al., 2009).

B. <u>Postpartum OCD</u>

While current evidence is insufficient to categorize Postpartum OCD as a distinct clinical subtype of OCD (McGuinness et al., 2011), the perinatal period is recognized as a time of increased vulnerability for the emergence of OCD symptoms, or the exacerbation of existing OCD, and is associated with a distinct clinical course (APA, 2013; McGuinness et al., 2011; Zambaldi et al, 2009). Reasons for increased vulnerability are unclear although theoretical explanations have been proposed. Fairbrother & Abramowitz (2007) posit that the peripartum period "lowers the threshold for OCD development/exacerbation by bringing with it a sudden and dramatic increase in responsibility for a vulnerable and highly cherished infant" (p.2158).

Hormonal changes also appear to influence OCD risk. Guglielmi and colleagues (2014) surveyed 542 women with OCD to assess the relationship between OCD symptoms and reproductive cycle events. Pregnancy and the postpartum period were associated with new-onset OCD for 5.1 and 4.7% of the sample, respectively, and 33 and 46.6% reported exacerbation of preexisting OCD during pregnancy and the postpartum period. Exacerbation in pregnancy and the postpartum during the first pregnancy were significantly associated with exacerbation and subsequent pregnancy and postpartum. However, participants also reported new onset OCD symptoms within 12 months after menarche (13%) and menopause (3.7%). Worsening of pre-existing OCD during the premenstrual period was reported in 37.7% of the sample, and 32.7% reported exacerbation of symptoms at menopause.

Regardless of etiology, OCD symptoms that surface during the postpartum period frequently involve intrusive thoughts related to harm to one's infant (Blakey & Abramowtiz, 2017; Frías et al., 2015; Jacob & Storch, 2013; Speisman et al, 2011). While occasional intrusive thoughts of harm coming to one's child are common among new parents, they do not occur with the same intensity, frequency, or accompanying psychological distress as experienced in postpartum OCD (Fairbrother & Abramowtiz, 2007; Frías et al., 2015; Miller et al., 2013; Zambaldi et al., 2009). In ppOCD, aggressive intrusive thoughts typically involve *directly* causing harm to the child, although thoughts of accidental harm may also occur (Jacob & Storch, 2013; Sichel et al., 1993; Speisman et al., 2011; Zambaldi et al., 2009).

In an early case series examining the clinical presentation of OCD in the postpartum period, all 15 mothers in the case series experienced intrusive thoughts or images of directly causing harm to their child. Common unwanted thoughts or images among several of the women included stabbing the child with a knife, drowning the child in a bath, or sexually abusing the child (Sichel et al., 1993). In a nonclinical sample of 400 postpartum women in Latin America, 9 percent of the sample was found to have clinically significant Obsessive Compulsive Disorder, as diagnosed by DSM-IV guidelines, with 2.3 percent reporting new onset (Zambaldi

et al., 2009). Participants with OCD had nine times the likelihood of experiencing aggressive intrusive thoughts when compared to their healthy peers (Zambaldi et al., 2009). In this sample, aggressive intrusions included thoughts or images of violent acts such as throwing boiling water on the baby, dropping the baby from height, or putting the child in the microwave oven (Zambaldi et al., 2009).

OCD symptoms during the perinatal period may also involve thoughts or images of accidental harm or illness coming to the infant (Jacob & Storch, 2013; Sichel et al., 1993; Speisman et al., 2011). Zambaldi et al. (2009) found that among women whose obsessions featured accidental harm, common intrusions included frequent thoughts or images of the infant dying in their sleep, falling from height, suffocating, or falling down the stairs. Some mothers also reported persistent fears of contamination, such as accidentally transferring chemicals from their hands to the child (Zambaldi et al., 2009). In these cases, clinically significant symptoms may be especially hard to self-identify and, consequently, treat--as mothers and their social supports may view their symptoms as normative anxiety or even excessive worry during a commonly stressful period, i.e. the postpartum.

As occurs with OCD at any point in the life cycle, obsessive intrusive thoughts are typically paired with behavioral compulsions to neutralize the unwanted thoughts and reduce anxiety. Compulsions correspond with the thought content and may include overt behaviors such as frequent checking of the baby's breathing, persistent reassurance seeking, or in the case of contamination thoughts, excessive washing and cleaning (Fairbrother & Abramowitz, 2007; Zambaldi et al., 2009). However, it is common for compulsions during the postpartum period to consist of covert mental processes such as mental rituals involving prayer or varied attempts at thought suppression (Fairbrother & Abramowitz, 2007). In the latter case, symptom and illness identification by both the mother and her social supports may be further complicated.

A small body of existing research suggests that OCD during the postpartum period may have a negative impact on the mother-child relationship. Mothers who experience aggressive

thought intrusions have reported deliberately avoiding caring for their child out of fear that will act upon the thoughts and harm their baby. For example, mothers who fear drowning their child may avoid bathing the baby altogether (Sichel et al., 1993; Fairbrother & Abramowitz, 2007). Children with mothers who have anxiety disorders may also be at greater risk of developing an insecure attachment style and developing anxiety disorders themselves in adulthood (Fairbrother & Abramowitz, 2007).

In one of the only published empirical studies on ppOCD, Challacombe et al. (2016) compared the parenting behaviors of 37 mothers with postpartum OCD and 6-month-old infants with 37 community control dyads. While both groups experienced some degree of intrusive thoughts related to the safety of the child, mothers in the OCD group experienced significantly more thoughts of intentional harm, contamination, thoughts of a sexual nature, and magical thinking about bad things happening to the baby, and were troubled by their symptoms a mean of 9.61 hours per day. Although infant temperament did not differ between groups, mothers with OCD were rated as less sensitive in mother-infant interactions, less confident, and less likely to be breastfeeding. Mothers with OCD also reported higher levels of marital problems and perceived less social support, suggesting that interpersonal relationships may suffer in the context of postpartum OCD (Challacombe et al., 2016). Despite the profound negative effects on the mother and her relationships, formal help-seeking for ppOCD is believed to be exceedingly low (Blakey & Abramowtiz, 2017; Frías et al. 2015; Speisman et al., 2011).

C. **Help-seeking for Mental Illness: Barriers to Care**

In order to understand the complex nature of help-seeking for OCD during the perinatal period, the interplay of societal, social, and individual factors affecting the help-seeking experience must be considered. Carillo et al (2011) identifies three broad barriers to access health services: Structural barriers; Financial barriers; and cognitive barriers. The following

section discusses the existing research on help-seeking among women with perinatal mental disorders and among individuals with OCD.

1. **<u>Structural Barriers to Care</u>**

Structural barriers to health care refer to the availability of the health care system, and may be experienced inside or outside of the healthcare system (Carillo et al., 2011). These typically include financial/insurance barriers, unavailability of childcare, proximity of health care sites, and transportation. Structural barriers encountered within the health care system itself may include long wait times, multiple locations for specialized care, multiple-step care processes, and lack of continuity of care (Carillo et at., 2011). Several quantitative and qualitative studies have identified structural barriers to seeking and receiving mental health care among women with symptoms of perinatal mental illness (Byatt et al., 2013; Fonseca, et al., 2015; Henshaw et al., 2013; Millet et al., 2017; O'Mahen & Flynn, 2008; Sword, et al., 2008).

For women with symptoms of perinatal emotional distress, structural barriers outside of the health system include transportation, inability to afford mental health care, lack of insurance/underinsurance, and lack of time to attend regular appointments (Fonseca et al., 2015; O'Mahen & Flynn, 2008). Within the health care system, long wait times for appointments, disjointed care pathways, and unresponsive providers have been found to inhibit help-seeking among women experiencing peripartum emotional distress (Byatt et al., 2013; Sword et al., 2008). Among studies that have explored the perspectives of obstetrician-gynecologists (OB-GYN) and other medical health care providers, lack of communication and collaboration with community mental health providers has been identified as a major barrier to care (Byatt et al., 2013). According to medical healthcare providers, reluctance or refusal of mental health providers to prescribe or continue psychiatric medications for pregnant women, or reluctance of pharmacists to fill those medications, is also problematic (Byatt, Biebel, Debordes-Jackson, et al., 2013).

2. **Knowledge Barriers**

Knowledge barriers frequently impede mental health care access among women with symptoms of perinatal emotional distress (Millett et al., 2017; Megnin-Viggars et al., 2015). Notably, women with perinatal mental health difficulties have consistently reported knowledge barriers as an impediment to care both before *and* after a mental health diagnosis was made (Megnin-Viggars et al., 2015). Initially, mothers may have difficulty identifying their mental health problems as a condition that can be treated, or in distinguishing their symptoms as distinct from normative stress and anxiety after childbirth (Jacob & Storch, 2013; Khan et al., 2014). Once symptoms are noticed, lack of knowledge about who to contact or where to go to get help has been reported as a major barrier to care (Megnin-Viggars et al., 2015; O'Mahen & Flynn, 2008). Study participants often report not receiving enough education and resources pertaining to postpartum mental health difficulties at outpatient prenatal visits and/or childbirth classes during the prenatal period (Byatt et al., 2013). Similarly, studies have found that women perceive a lack of guidance and support with how to follow up on referrals from general practitioners, obstetricians, midwives, and other medical personnel have led to reduced help-seeking behaviors after clinical diagnosis or screening positive for a mental disorder (Henshaw et al., 2013; Megnin-Viggars et al., 2015; Millett et al., 2017).

Women's lack of knowledge about available treatment options and their alternatives also influence their expectations and attitudes about mental health treatment. In a quantitative study with 108 pregnant or postpartum women who screened positive for peripartum depression, O'Mahen & Flynn (2008) found lack of motivation to seek treatment and feelings of hopelessness that treatment would be effective to be prevalent care barriers. Another more recent study produced similar findings, with lack of motivation topping the list of attitudinal barriers (Prevatt & Desmarais, 2018). Negative attitudes toward pharmacotherapy during pregnancy or lactation also influence women's willingness to engage in mental health treatment,

especially if they perceive medication to be a necessary (or mandated) component of peripartum mental health treatment (Byatt et al., 2013; Sword et al., 2008).

The process of seeking help for mental illness during the perinatal period may be especially complex, and warrants further research attention (Patel & Wisner, 2011). To date, much of the research on help-seeking for perinatal mental illness focuses on identifying structural barriers and facilitators to care (e.g. Millet et al., 2017; O'Mahen & Flynn, 2008), with less consideration of how the dynamic process of mental illness-related help-seeking unfolds. For example, lack of screening protocols has often been cited as a barrier to mental health care among women with perinatal mental illness (e.g. Misri et al., 2015). However, screening and assessment procedures alone do not ensure that women will receive needed care for their perinatal mental health difficulties (Henshaw et al., 2013). While depression screening during the peripartum period is now common in many areas, less than 30% of women who screen positive for depression will ever attend a mental health appointment (Henshaw et al., 2013; Smith et al, 2009). In fact, several studies have found the rates of professional help-seeking after a positive peripartum depression screen to be less than 15 percent (Fonseca, Gorayeb, & Canavarro, 2015; Dennis & Chung-Lee, 2006; Patel & Wisner, 2011). Further, It is well-documented that women experiencing perinatal emotional distress sometimes do not disclose their symptoms, or even actively try to hide their symptoms from both providers and social supports out of fear of negative consequences or shame (Byatt et al., 2013; Frías et al., 2015; Khan, 2015; Sword et al., 2008). In the case of ppOCD, concealing symptoms from the social support network may be even more prevalent due to the disturbing and ego-dystonic nature of aggressive intrusive thoughts (Frías et al., 2015; Speisman et al., 2011). Thus, several internal and external factors may influence women's decisions to seek and receive care, as well as impact their health care experiences.

   D. **Stigma and Perinatal Mental Illness**

Public stigma surrounding mental illness remains a serious social problem, adversely affecting the quality of life and opportunities of individuals with mental disorders. While advocacy efforts and public education campaigns have heightened the public's awareness and understanding of mental illness, negative perceptions and discrimination at the individual and structural level abound (Pescosolido & Martin, 2015). While some research suggests that individuals experiencing perinatal mood and anxiety disorders may not necessarily be heavily *publicly* stigmatized (Kingston et al., 2014) this population experiences high levels of perceived- and self-stigma, which affect the process of symptom disclosure as well as informal and formal help-seeking (Fonseca et al., 2015; Pinto-Foltz & Logsdon, 2008; Mickelson et al., 2017).

Self-stigma refers to the internalization of the experience of stigma and often results in detrimental effects on one's self-esteem and self-efficacy (Corrigan et al., 2006). The internalization of stigma may be perpetuated by the social standards of motherhood projected by society in addition to the practice of "blaming the mother for undesirable outcomes independent of her choices" (Pinto-Foltz & Logsdon, 2008, p.29). Internalized stigma then may result in decreased parenting efficacy, self-efficacy, and lowered self-esteem (Henderson, Harmon, & Newman, 2016; Pinto-Foltz & Logsdon, 2008; Mickelson et al., 2017).

Fear of stigmatization and negative evaluation by others is consistently found to be a major barrier to care among women with perinatal mental health disorders (Byatt et al., 2013; Fonseca et al., 2015; Millett et al., 2017; Prevatt & Desmarais, 2018; Sword et al., 2008). Among women experiencing perinatal mental illness, the experience of stigma is associated not only with having a mental illness, but with being regarded as an unfit parent or feeling shame about pronounced emotional distress during a time that is supposed to be happy and joyful (Patel, Wittkowski, Fox, & Wieck, 2013; Mickelson et al., 2017). The effects of stigma are exacerbated due to the prominent focus on "the myth of the perfect mother" idealized in contemporary Western society (Tummala-Narra, 2009, p.8). In the current social context, the role of the mother is constantly in question. On one hand, challenging traditional gender roles

has afforded women greater freedom and opportunities in career, relationships, and leisure. From a societal standpoint, the limits on what a mother can and should do with her life are disintegrating, and the resulting freedom to choose one's life path can be deeply empowering (Tummala-Narra, 2009). However, many women internalize the message that they can do it all to mean that they *should* do it all, resulting in high levels of psychological distress at perceived failures to uphold the standard of idealized motherhood. Advances in technology have allowed for the easy dissemination of the latest research on "good" parenting, attachment, and infant well-being, much of which focuses on the importance of the mother-child relationships and emphasizes a style of parenting that has been termed "intensive mothering". The concept of the idealized mother has been shown to have deleterious impacts on the mental health and well-being, self-esteem, and self-efficacy of modern mothers (Henderson et al., 2016).

For example, qualitative studies on mental health help-seeking among postpartum women reflect the profound influence of the perception of idealized motherhood on help-seeking. In a qualitative meta-analysis examining barriers to care among diverse international populations, Dennis & Chung-Lee (2006) identified "various conceptualizations of the maternal role as barriers to women seeking help" (p.325). Women may avoid disclosing their symptoms and seeking help in order to avoid appearing weak or unable to perform their roles and responsibilities as a mother (Dennis & Chung-Lee, 2006). In a qualitative study with mothers who had been diagnosed with peripartum depression, Patel et al. (2013) found that participants were fearful of receiving a formal label of postpartum depression, and exhibited high levels of perceived and internalized stigma:

> There was a sense that the stigma attached to mental health problems was elevated for these mothers...being labeled with PND [perinatal depression] was scary because it reinforced the threatening nature to their self-concepts as mothers. Participants believed that label would lead to multiple negative views from others as weak, not normal,

unpredictable, not functioning, not in control, and not able to care for or love their child

(p.686).

In a focus group study that gathered the perspectives of 27 postpartum women who had experienced depression, anxiety, or other emotional distress, Byatt et al. (2013) found that postpartum women were "reluctant or 'terrified' to acknowledge mental health concerns to family, friends, or health care professionals due to shame, guilt, and pressure to be a 'super mother' who can 'do it all'" (p.599). Similarly, in another qualitative study with women who had postpartum depression, Sword et al. (2008) found that participants expressed fears of being perceived as a "bad mother" if they disclosed their symptoms.

Closely related to the fear of being regarded as an unfit mother is the pervasive fear of child apprehension and/or custody loss, which has been identified as a major deterrent to symptom reporting during the perinatal period in multiple studies (Byatt et al., 2013; Fonseca et al., 2015; Howard et al., 2014; Khan, 2015; Megnin-Viggars et al., 2015; Millett et al., 2017; Sword et al., 2008). Among women who had experienced postpartum mental health difficulties, Prevatt & Desmarais (2018) found stigma to be the most commonly endorsed barrier that made it "extremely difficult" or "impossible" to disclose symptoms to a health provider. Byatt et al. (2013) found that participants intentionally concealed intrusive thoughts of harm to self or others for fear of consequences or lack of understanding from providers. For example, one mother related, "I could not tell them my specific symptoms...in terms of throwing your kid against the wall or stabbing them or whatever...Even though I wasn't gonna do it, I had these images of it" (Byatt et al., 2013, p.600). While aggressive intrusive thoughts occur in some severe cases of postpartum depression, these thoughts are a hallmark feature of postpartum OCD. In the case of postpartum OCD, concealing symptoms may be even more prevalent due to the disturbing and ego-dystonic nature of aggressive intrusive thoughts involving one's child (Spiesman et al., 2011).

E. Conceptual Framework: The Network Episode Model

Help-seeking for ppOCD may be viewed through multiple lenses in the broader research context of help-seeking for mental illness in addition to perinatal mental illness and OCD specifically. To this end, the Network Episode Model (NEM; Pescosolido 1991) is utilized as a sensitizing framework in this dissertation research. Key concepts drawn from the NEM informed the development of the present study's research questions and interview guide, and informed the latter stages of data analysis. The following section will present the major tenets of the NEM, as well as how it has been previously applied to mental health help-seeking research.

1. Origins and Development

The NEM was initially developed to explore how formal and informal social support systems influenced the treatment-seeking process of adults with mental illness. Historically, help-seeking for mental illness has been conceptualized to consist of rational, individual choices that occurs relatively independent of social influence (Pescosolido et al., 1998). Advances in social science research have led to new conceptualizations of help-seeking that acknowledge the complexity and interconnectivity of social, structural, and individual factors in making health care decisions (Pescosolido, 2011). Help-seeking, then, is a dynamic process that is unavoidably influenced by the social context in which the individual is situated. The NEM was developed to improve upon the limitations of previous models of healthcare decision-making (e.g. Andersen's [1968] Socio-behavioral model) that conceptualize decision-making as a highly individual process (Pescosolido, 1991).

Developed specifically to account for the complexity of the decision-making process in seeking help for mental illness, the NEM views healthcare decision-making in the context of a dynamic "illness career", a trajectory along which a multitude of individual, social, and structural factors may influence the help-seeking journey. The *illness career* recognizes a multi-stage process whereby individuals: 1) come to recognize their mental illness; 2) decide whether or not

to utilize healthcare; 3) decide to follow through on medical advice; 4) experience a medical outcome; and 5) decide to follow through on long-term treatment advice. Each stage represents a dynamic period wherein a multitude of decisions about healthcare may be made (Pescosolido, 1991).

In this model, support networks are activated when individuals' coping ability becomes overwhelmed, and the activation of social networks occurs as a coping mechanism during a mental health crisis (Berry & Pescosolido, 2015). The characteristics of the episode of the illness influences the activation of social networks, which in turn influences illness career, or the individuals' trajectory through the health system. In this context, social network activation may be beneficial and protective if informal and formal supports are supportive and promote help-seeking engagement. Conversely, social network activation can be detrimental to mental health outcomes if individuals receive negative, indifferent, or stigmatizing reactions during social interactions (Berry & Pescosolido, 2015).

2. <u>Application of the Network Episode Model</u>

The Network Episode Model, and the associated concept of the of the illness career, has been applied as a sensitizing framework in previous studies that have explored the decision-making process of mental healthcare utilization among diverse populations from varied social contexts. The NEM and the associated concept of the illness career may be especially useful for understanding the help-seeking process among individuals with illnesses or from social contexts that are commonly misunderstood or heavily stigmatized. For example, Long et al. (2015) used the NEM as a lens through which to view the help-seeking process of community members with self-injurious behaviors. Researchers found that among individuals who self-injure, external barriers to care (e.g. stigma, judgment, and misunderstanding) influence internal barriers such as fear, doubt, and shame, which in turn affects individuals' self-perceptions, as well as future decisions about symptom disclosure and formal treatment participation (Long et al., 2015).

Thus, decisions to participate in treatment were mediated by the individual's emotional state as they interpreted-and internalized- the meaning of their social interactions. Consistent with the tenets of the NEM, individuals' process of help-seeking did not proceed in a linear fashion, and was continually influenced by external barriers as well as internal emotional fluctuations toward the idea of seeking and receiving help.

The NEM recognizes both treatment providers and informal social supports (e.g. family and friends) as members of an individual's social network. According to the NEM, individuals activate their social networks in times of mental health crisis, when they have exhausted their coping skills. The nature of the interactions with social network members directly influence the individual's health care decision-making process and their trajectory through the health system (Pescosolido, 1991) throughout an episode of illness. In the context of perinatal mental disorders, studies have found that the interactions between health providers, mothers, and other support network members can both facilitate and hinder the help-seeking process (Dennis & Chung-Lee, 2006).

3. **Informal Support Network**

Social support is provided by members of the individual's social network. For perinatal women, common sources of social support include the woman's partner, the woman's mother, birth professionals, other family (e.g. sister), and friends (Henshaw et al., 2013; Razurel & Kaiser, 2015). Strong social support during the peripartum period has been shown to be a protective factor against peripartum mood and anxiety disorders (Dennis et al., 2017; Pilkington et al., 2016; Reid & Taylor, 2015). With regard to postpartum depression, peer support has been shown to be beneficial for alleviating depressive symptoms (Evans et. al, 2012). Conversely, poor social support is a known risk factor for the development and maintenance of perinatal mental health problems (Challacombe et al., 2009; Goodman et al., 2016; Prevatt & Desmarais, 2018). Compared to the antepartum period, recent research suggests that the postpartum

period may be associated with the perception of decreased social support and a decreased social network size (Asselman et al., 2016). In a quantitative study that explored the treatment-seeking experiences of women who had screened positive for postpartum depression, participants self-identified inadequate social support to be the primary cause of their postpartum depressive symptoms (Henshaw et al., 2013). Low social support is also known to be associated with high levels of anxiety symptoms during the peripartum period (Asselman et al., 2016; Dennis et al., 2017). Results from a meta-analysis of postpartum anxiety disorders indicate that low social support is a risk factor for the development of anxiety disorders (Goodman et al., 2016). In one study that assessed factors involved with prolonged postpartum anxiety, Dennis et al. (2017) found that along with high perceived stress, poor social support was the top factor associated with sustained (as opposed to single occurrence) postpartum anxiety.

In some studies, women have expressed preferences for receiving help for their mental health problems from their informal support network in lieu of seeking out professional mental health care (Henshaw et al., 2013; O'Mahen & Flynn, 2008). Thus, help-seeking among women experiencing peripartum emotional distress may be viewed as "a graduated process in which private, casual deliberations are common among women with elevated symptoms, and public, formal actions are rarer" (Henshaw et al., 2013, p.175). However, it has also been noted that women sometimes do not disclose their symptoms to their social supports for fear of judgment or negative evaluation (Howard et al., 2014; Khan, 2015).

Increasingly, members of internet support groups are becoming sources of social support. A content analysis of members' remarks to one another on an online support forum for postpartum depression revealed that members often acted as "peer experts" who provided one another with advice and encouragement based upon their own experiences (Evans et al., 2012). The anonymity element of online forums has been found to alleviate the fear of stigmatization often found among women experiencing peripartum mental health disorders. For example,

Evans et al. (2012) found that participation in an online social support group "provided a safe place to reveal negative thoughts about motherhood that tend to be viewed as socially objectionable" (p.408).

In addition to utilizing them as sources of direct informal support, women experiencing symptoms of perinatal mood and anxiety disorders often rely on their support networks to assist in making decisions about how to respond to their symptoms, including decisions about symptom disclosure and treatment-seeking. In a quantitative study with 100 pregnant and postpartum women who had been diagnosed with MDD by a medical provider, Patel & Wisner (2011) found that participants expressed a strong preference for an active, collaborative role with their main social supports in the treatment decision-making process. Women's partners and mothers may play an especially important role in the decision-making process (Henshaw et al., 2013; Razurel & Kaiser, 2015). Interestingly, women and members of their support network often have different ideas about the existence of mental health symptoms, as well as their causes (Henshaw et al., 2013). Hence, studies have found that social supports can both facilitate and deter professional help-seeking for mental health problems during the perinatal period (Byatt et al., 2013; Sword et al., 2008).

4. **Formal Support Network: Health institutions and Providers**

Many women do not seek out specialty mental health care without a referral from another health provider (Khan, 2015). Health provider's lack of knowledge about postpartum mental health and illness has acting as a deterrent to accessing mental health care (Dennis & Chung-Lee, 2006; Khan, 2015). In a British study that surveyed 43 general practitioners about their confidence in detecting postpartum mental health issues, roughly half of the participants indicated that they were not confident in their ability to detect mental illness among women (Khan, 2015). In a United States study, O'Mahen & Flynn (2008) analyzed electronic health records to determine obstetrical providers' detection rates of depression and anxiety during

pregnancy and two months postpartum. Of the 51 women who screened positive for depression or anxiety during the 6-week postpartum visit, only 15 women had any documentation of psychiatric symptoms or diagnoses in the EHR at 8-weeks postpartum. At two months postpartum, only 25% of patients who screened positive for mental health issues had received pharmacological or psychological treatment (O'Mahen & Flynn, 2008). In several studies, providers failing to follow-up on positive depression screens or provide referrals for mental health treatment deterred further care-seeking among women who screened positive for postpartum depression (Byatt et al., 2013; Henshaw et al., 2013; Sword et al., 2008). Conversely, provider outreach and follow-up has been shown to facilitate continued help-seeking behaviors after a positive peripartum depression screen (Sword et al., 2008).

For those who do report symptoms to health care providers, the nature of the interaction with the provider has been shown to affect further help-seeking. Stigmatizing reactions from mental health providers (i.e. psychiatrists, therapists) have been shown to deter both mental health treatment-seeking and treatment adherence among individuals with mental illness (Corrigan et al., 2014). In a number of studies, women seeking help for symptoms of emotional distress during the peripartum perceived that they were met with dismissive, disrespectful, or judgmental reactions from providers (Byatt et al., 2013; Henshaw et al., 2013; Prevatt & Desmarais, 2018).

Qualitative studies have found that health care providers "normalizing" expressed symptoms deterred further help-seeking among women who screened positive for postpartum depression (Byatt et al., 2013; Sword et al., 2008). In a retrospective study with 36 women with clinically significant postpartum depression and anxiety screens, less than a quarter of the participants who had discussed their symptoms with their doctor recalled receiving a referral for mental health treatment (Henshaw et al., 2013). Other studies have found that women may find interventions (e.g. pharmacotherapy, outings with friends) suggested by medical providers who

do not specialize in mental health to be inappropriate or unrealistic (Byatt et al., 2013; Sword et al., 2008).

In response to the alarmingly low rates of formal help-seeking for postpartum mental health difficulties, numerous quantitative and qualitative studies have explored the barriers and facilitators to help-seeking among perinatal women. These studies have provided useful insights into the influence of stigma at the individual and structural level, the importance of the provider-patient interaction in guiding help-seeking decisions, and the role of informal social supports in the help-seeking process (Dennis & Chung-Lee, 2006; Millett et al., 2017; Sword et al., 2008). However, most of these studies have been conducted with, or in reference of, women with postpartum depression, or with women experiencing unspecified emotional distress during the peripartum period. While it is likely that some of these samples were comprised of women who were indeed experiencing obsessive-compulsive symptoms, no published studies have intentionally explored the experiences of help-seeking among women with postpartum OCD. The following section reviews the small body of research on the lived experience of OCD as it relates to help-seeking.

F. <u>Help-Seeking for Obsessive-Compulsive Disorder (OCD)</u>

OCD is among the most publicly misunderstood mental health conditions (Coles et al., 2013; Davis et al., 2018; Robinson et al., 2017). OCD is associated with long delays—or complete absence—of formal treatment-seeking among symptomatic individuals (Belloch et al., 2009; Fennell & Liberato, 2007; Murphy & Perera-Delcourt, 2012). Average time between onset of OCD symptoms and beginning treatment has been found to range from 3 (Belloch et al., 2009) to 17 years (Pinto et al., 2006). In the few studies that have specifically explored help-seeking barriers in the context of Obsessive Compulsive Disorder, lack of awareness of the condition and its symptoms consistently emerges as a prominent barrier to care access (Belloch et al., 2009), as does fear of stigmatization (Fennel & Liberato, 2007; Murphy & Perera-

Delcourt, 2012; Robinson et al., 2017). To date, very few qualitative studies have examined the process of help-seeking among individuals with OCD (Robinson et al, 2017). The following section will discuss the studies that have explored help-seeking behaviors and conceptualizations among individuals with OCD.

1. **Perception and Fear of Public Stigma**

Perception and fear of public stigma about OCD is perhaps the most salient barrier to help-seeking among individuals with OCD (Murphy & Perera-Delcourt, 2014; Robinson et al., 2017). Individuals with OCD symptoms have been known to exert great efforts in concealing their symptoms from family, friends, and help-providers. In fact, this tendency is so prevalent that OCD is often referred to as "the secret illness" (Robinson et al., 2017; Salkovskis, 1990). In one of the few qualitative studies documenting the lived experiences of individuals with OCD, Murphy & Perera-Delcourt (2014) utilized interpretive phenomenological analysis (IPA) approach to explore how individuals conceptualized their OCD experiences, as well as how they perceived the treatment process. Participants expressed a deep sense of personal failure in multiple areas of their lives with regard to their condition, especially in social and intimate relationships (Murphy & Perera-Delcourt, 2014). In this study, participants spoke of both external sources of stigma and internalized stigma as a barrier to care, and engaged in frequent social comparison with peers.

> Participants' accounts indicated that they not only felt rejected outwardly by others but rejection from others became internalized...forms of self-stigma became apparent as participants became frustrated and dissatisfied with themselves when they did not follow through on age-appropriate life goals" (Murphy & Perera-Delcourt, 2014, p.121).

Robinson et al. (2017) also identified fear of stigma to be a major barrier to care in the context of several relationships and situations. Some of the participants described keeping their symptoms secret from both their families and partners for several years, including one participant who had

intrusive thoughts of harming her children. Some participants wanted to "shield their families from the knowledge that they had a mental illness"(p.201), while others who did disclose their condition reported family members did not want to acknowledge their illness. In reference to health provider interactions, most participants reported that they did not disclose their symptoms because they were embarrassed or ashamed to describe them, and many avoiding treatment-seeking because they did not want a diagnosis of OCD on their medical record. Individuals who experienced aggressive intrusive thoughts of harming others, did not disclose their symptoms to providers out of fear of criminalization, and in the case of parents--child apprehension (Robinson et al., 2017).

2. <u>**Knowledge Barriers**</u>

Barriers to help-seeking involving lack of knowledge about the illness and treatment appear to be present across diverse cultural contexts and health care systems. For example, in a quantitative study that assessed help-seeking behaviors among individuals diagnosed with OCD in Spain, Belloch et al. (2009) found an average delay of 39 months from the onset of symptoms to receiving a diagnosis. Although all study participants experienced their symptoms as problematic from onset, and did not differ on measures of symptom severity, long (versus short) delays in seeking treatment were associated with less knowledge about OCD in general, and less insight into the effects of symptoms on their personal lives in terms of life interference, mood, and behavior changes. Conversely, participants who sought treatment earlier reported a greater awareness of dysphoric mood, fear, and general unpleasantness associated with their symptoms (Belloch et al., 2009). One qualitative study conducted with Hawaii residents found that individuals faced significant struggles in both identifying their illness and accessing appropriate health care services, reflecting both cognitive and structural barriers to mental health care access:

> Hawaii is often held up as an exemplar for enlightened healthcare, and yet without exception each of the participants shared tremendous challenges in being able to accurately name their illness and an equally difficult struggle to receive evidence-based treatment (Olson et al, 2007, p.567).

In a UK study, Robinson et al. (2017) found similar results, with several participants reporting that they or their families realized there was problem, e.g. that their personality was "a bit strange" (p.202), but they did not realize that their symptoms were signs of a treatable illness. Others have reported not knowing where to go to get treatment, as well as encountering mental health providers with limited OCD knowledge who did not know how to effectively treat the illness (Olson et al., 2007).

3. <u>Resistance to Treatment Interventions</u>

Finally, reluctance to utilize established treatment protocols has also emerged as a barrier to care among individuals with OCD. Study participants report resistance to pharmacological intervention (Robinson et al., 2017) as well as Cognitive-Behavioral psychological treatment (Murphy & Perera-Delcourt, 2014; Robinson et al., 2017). The gold standard for OCD treatment, Exposure with Response Prevention (ERP), while highly effective, is often experienced to be a harsh modality, requiring individuals to confront their worst fears (the obsessive thought content) without engaging in safety behaviors (compulsions). As a result, some individuals view the therapeutic process for OCD as too difficult to endure (Murphy & Perera-Delcourt, 2014; Olson et al., 2007; Robinson et al., 2017). Murphy & Perera-Delcourt (2014) reported that multiple participants were discouraged by the restrictions of CBT/ERP, and felt they could not freely explore the psychosocial origins of their illness, given the modality's present moment focus. For some individuals, feeling dismissed in this way led to strain in the therapeutic relationships (Murphy & Perera-Delcourt, 2014).

G. <u>Conclusion: Help-Seeking for ppOCD</u>

PPOCD is an under-recognized and misunderstood condition that can have a severe negative impact on the quality of life of mothers and families (Frías et al., 2015; Jacob & Storch, 2013; Speisman et al., 2011). Mental illness during the perinatal period and OCD are associated with especially low rates of treatment seeking, active attempts to conceal symptoms from social supports and providers, and high amounts of perceived and experienced stigma. Thus, the process of seeking help for ppOCD may be rife with yet unexamined challenges and complexities. In order to develop practice and policy that more adequately address the needs and concerns of women with ppOCD, more research is needed to understand the lived experiences and help-seeking behaviors of these mothers. Applying the NEM as a sensitizing framework, this dissertation research utilized a qualitative interpretive phenomenological research approach to gain an in-depth understanding of the lived experiences of mothers who have experienced and sought help for ppOCD.

III.   RESEARCH METHODOLOGY

In the phenomenological sense, lived experience may be understood as an "awareness of life without thinking about it, a pre-reflexive consciousness of life that when remembered, gathers interpretive significance" (Taylor, 2013, p.84). Qualitative researchers use phenomenological approaches to describe and interpret the meanings of specific lived experience, to arrive at the individual and shared meaning of the experience (van Manen, 1997). In the social and health sciences, phenomenological approaches are utilized in exploratory studies when the study objective is to gain a richer, deeper understanding of a specific phenomenon of which little is known, often to inform practice and/or policy development or implementation (Creswell & Poth, 2018; van Manen, 1997). In this exploratory dissertation study, I utilize a qualitative, interpretive phenomenological research design to explore mothers' lived experiences with having and seeking help for postpartum OCD, a serious maternal mental health condition that is not yet widely recognized nor understood.

This chapter begins with a brief overview of phenomenology, immediately followed by the rationale for using interpretive phenomenological methods in this dissertation research. Next, I discuss my positionality and reflexive practice, elucidating how my own preunderstandings of the phenomenon influenced the study's conceptualization, data collection process, and interpretation of the data. The latter half of the chapter provides detailed information on the study's design and implementation. The chapter concludes with a discussion of the procedures employed to ensure trustworthiness and scientific rigor, as well as ethical considerations which emerged throughout the research process.

A. **Research Design: Interpretive Phenomenological Approach**

In qualitative phenomenological research, the specific type of phenomenological method to be used and the related philosophical underpinnings should be presented, as distinctions drive methodological and analytical decisions (Lopez & Willis, 2004). The following section will

describe the use of phenomenology as a broad research method, discuss the philosophical origins of phenomenology, present the basic tenets of Heidegger's (1962) interpretive phenomenology, and will conclude with a rationale for the selection of interpretive phenomenological methods for this dissertation study.

1. <u>Phenomenology as a research method</u>

Phenomenological research methods are indicated when it is important to understand the shared and unique experiences of individuals who have experienced a common phenomenon (Creswell & Poth, 2018; Moustakas, 1994). Phenomenology as a qualitative *research method* endeavors to describe, and in some approaches, interpret, participants' lived experiences to develop an "essence" of a particular phenomenon (Creswell & Poth, 2018; van Manen, 1997). Features common across all types of phenomenological studies include: A clearly defined phenomenon to be studied; an exploration of the phenomenon of a heterogeneous group who have all experienced the common phenomenon; and recognition of both unique individual experiences as well as common experiences among those who have experienced the phenomenon (Creswell & Poth, 2018). This dissertation research utilizes an interpretive phenomenological approach, largely influenced by the interpretive phenomenology of Martin Heidegger (1962).

2. <u>Husserlian Phenomenology</u>

The term "Phenomenology" originally referred to a branch of Philosophy concerned with the account of subjective lived experience to arrive at the "essence" of that experience and uncover meaning, and was not initially conceptualized as a method of conducting research (Lopez & Willis, 2004; Moustakas, 1994). While multiple philosophers contributed to the development and advancement of phenomenology as a philosophy, Edmund Husserl (1913/1931) is most often credited as the founder of phenomenology (Hanna et al., 2016; Moustakas, 1994). In conceptualizing phenomenology as a form of inquiry, Husserl sought to

create a method to understand human experience as fully as possible without the influence of previous scientific inquiry or personal bias (Moustakas, 1994). Moran (2000) describes the philosophical conceptualization of phenomenology as:

> A radical, anti-traditional style of philosophising, which emphasises the attempt to get to the truth of matters, to describe *phenomena,* in the broadest sense as whatever appears in the manner in which it appears, that is at it manifests itself to consciousness, in the experiencer (p.4).

While all types of phenomenology value the focus on lived experience as a way to generate knowledge and meaning, the early 20th century phenomenological philosophers disagreed on the specific ways to conduct and interpret phenomenological inquiry (Moran, 2000). Husserl (1913/1931) maintained that through a process termed phenomenological reduction, one could "transcend" his or her own preconceptions or pre-existing knowledge concerning a particular human experience and come to understand the phenomenon anew, through only the description of the lived experiences of those who had experienced the phenomenon (Moustakas, 1994). According to Husserl, the "essence" of lived experience is gleaned through the generation of rich descriptions of the experience of a phenomenon as it arrives in the individual's consciousness. In Husserl's [transcendental] phenomenology, a rich enough description of an individual's lived experience requires no further interpretation to reveal underlying meaning (Moustakas, 1994).

3. **Interpretive/Hermeneutical phenomenology**

Martin Heidegger, a student of Husserl, is associated with the interpretive branch of phenomenology, strongly influenced by the study of hermeneutics, and sometimes referred to as hermeneutical phenomenology (Lopez & Willis, 2004; Moran, 2000). While Husserl's phenomenology focused on only the individual's *conscious* experiences, an interpretive approach to the study of lived human experience rejects the notion that the *meaning* of

experience is always available within one's conscious awareness. Lopez & Willis (2004) state that hermeneutical inquiry "goes beyond mere description of core concepts and essences to look for meanings embedded in common life practices...these meanings are not always apparent to the participants but can be gleaned by the narratives produced by them" (p.728). Heidegger (1962) contended that an individual's description of a particular phenomenon would necessarily be shaped by the individual's "lifeworld", comprised of such elements as the historical time and setting, his or her social environment, and personal experiences. While Husserl believed that it was possible for the inquirer (i.e. the researcher) to "bracket", or section off, his or her personal experiences and previous knowledge related to the phenomenon being studied, Heidegger believed that it was impossible for the interpreter to completely rid him or herself of presuppositions, and that the experiences and knowledge of the researcher would definitely influence the interpretation, due to the nature of our existence, or what he called being-in-the-world (Heidegger, 1967; Tan et al.,, 2009).

B. <u>Rationale for the Use of Interpretive Phenomenology</u>

When considering methodological options for this dissertation research, I considered my own reasons for exploring this topic. First and foremost, I have a desire to more deeply understand the way that women experience ppOCD, and how those experiences shape their help-seeking journey. I hope that this study can raise awareness of this little-known and oft misunderstood postpartum disorder, and thus encourage future research into this area that may influence current system and provider-level health practices and policies that promote increased education about postpartum OCD, as well as facilitate symptom disclosure and help-seeking. According to Creswell & Poth (2018) phenomenological methods are appropriate when there is relatively little known about a particular phenomenon, and as such, may be useful in informing future empirical research and practice and policy development.

With regard to the specific branch of phenomenology, I choose interpretive phenomenology because it is more closely aligned with the interpretive paradigm of reality, to which I personally align with and which formed the basis for the conceptualization of the study. The interpretive paradigm assumes that reality is socially constructed and aims to understand the experience of people from their own perspectives, while acknowledging that subjective experiences of the same event or phenomenon may be highly variable (Hennink et al., 2011). Further, Interpretive phenomenological approaches align with the core Social Work concept of "person-in-environment", wherein we are always encouraged to consider the ways in which the individual's experience is shaped by intra- and inter-personal factors as well as their external social environment. The study's theoretical framework, the Network Episode Model (Pescosolido, 1991) also assumes an interpretive worldview, as a key concept of the NEM involves the way in which an individual's social context and interpersonal interactions influence their help-seeking journey.

C. Role of the Researcher and Reflexivity

Interpretive paradigms assume that research is not inherently "value-free" and that the researcher, as the instrument of data analysis, will influence data collection, selection, and interpretation to some extent (Hennink et al., 2011). Further, interpretive phenomenological approaches, specifically, assume that the researcher's lived experiences, knowledge, and other preunderstandings contribute to the collaborative process of meaning-making between researcher and participant (Heiddeger, 1962; van Manen, 1997). Although preunderstandings cannot be separated fully from the research context, they can be made explicit through a reflexive process of self-examination throughout the entire research process (Finlay, 2002; van Manen, 1997).

Given the emphasis on approaching the phenomenon with openness and wonder (i.e., the 'phenomenological attitude'), reflexive practice may be *especially* important in the pre-

research phase of phenomenological studies, when the study is being conceptualized and designed (Finlay, 2002; 2008). To illuminate how this study came into being and acknowledge the role of my preunderstandings, I discuss my personal experience, social positioning, and pre-existing knowledge base in relation to the phenomenon. In doing so, I assume a narrative voice, so that I may communicate my experiences in an authentic manner, as they were lived (van Manen, 1997).

1. **Experience with the Phenomenon**

I began conceptualizing this dissertation research after experiencing, and later seeking help for, new-onset Obsessive Compulsive Disorder (OCD) following the birth of my oldest child in February of 2017. During this time, I experienced persistent, disturbing, intrusive thoughts related to my child's safety and wellbeing, as well as compulsive mental rituals to "erase" or "undo" the thoughts. Deeply distressed by these experiences, I did not disclose my thought content to anyone, and consciously attempted to conceal my symptoms from my husband, other family members, and health providers.

As a clinical social worker who has some experience working with individuals with an OCD diagnosis, I did recognize that some elements of my experience resembled OCD. However, as far as I knew, I didn't *have* OCD, and I had no knowledge that it could emerge postpartum. While I was well aware of the risk for postpartum depression, or even postpartum generalized anxiety, postpartum OCD was simply not on my radar—never throughout the course of my professional training, clinical practice, or childbirth/postpartum preparation (i.e., self-study and health system-sponsored education/preparation courses) had I ever come across the concept. In fact, I was afraid to even conduct a cursory internet search for "OCD symptoms postpartum", for fear that I would learn that I did *not* have a treatable mental illness, but rather something was simply "wrong" with me. While some family members noticed my high anxiety

levels and encouraged me to seek help, I did not disclose my thought content, nor seek help, for eight months after symptom onset.

2. <u>Social and Professional Positionality</u>

In recognition of my relative privilege, my utilization of high-quality health care may not mirror the encounters of other women. Though not to dismiss any personal hardships that I experienced, a woman's journey in help-seeking must be contextualized in the structural barriers that may exist. Considering the availability of childcare, transportation, and economic means within my experience of help-seeking, I had relative ease in accessing a psychologist who specialized in OCD and practiced five minutes from my home *within days of making the inquiry*. When I learned that the provider I wanted to see was out-of-network with my health insurance, my husband and I had financial means to afford out-of-pocket expenses. Seeking help as a white, middle-class, heterosexual, cisgender woman, I was fortunate to not experience a harsher form of discrimination that others live daily within the U.S. healthcare system, nor was I ever fearful of that possibility.

Ample social support from family and peers and access to a robust professional network of healthcare providers allowed me to navigate mental health systems with relative ease. My husband was supportive and encouraged me to seek help. My mental health literacy and clinical knowledge allowed me to quickly identify appropriate providers, as well as rule out those whose expertise may not be as relevant. Further, I was able to communicate my experience to the psychologist using clinical terms, which allowed for a quick confirmation of my provisional self-diagnosis; it was, in fact, OCD. And yes—she does see it a lot postpartum (M. Zayed, personal communication, August, 2017).

3. <u>Knowledge Base</u>

In my role as a clinical social worker, I have worked in diverse health care and community practice settings, mainly in the capacity of an individual, family, and group

psychotherapist. My ideas about mental illness and help-seeking have been largely shaped by my professional experiences—including both my interactions with individual clients and their families as well as health/mental health institutions. While structural and institutional barriers to care access and utilization are significant, I perceive psychosocial factors, such as shame amidst public and internalized stigma about mental illness and motherhood, to be equally significant. Over the course of the past decade, I have supported diverse clients in their struggle to make sense of enigmatic mental illness. I have come to understand, through hearing my clients' stories, that the experience of shame can have a profound effect on symptom disclosure and further help-seeking, especially when the illness is not well-understood or heavily stigmatized. After familiarizing myself with the maternal mental health and help-seeking literature, I uncovered significant gaps in postpartum OCD research. Over the next few months, I asked various health providers (obstetricians/gynecologists, pediatricians, family practitioners, clinical psychologists, Licensed Clinical Social Workers) about their familiarity with OCD during the pregnancy and/or the postpartum period. The responses I received, coupled with my own previous lack of awareness, emphasized the need for more research and knowledge generation.

Taken together, these areas form the base of the preunderstandings I brought to the design of this research. My own experiences with ppOCD, paired with my interest in clinical social work and influences on help-seeking behavior, influenced the study's overarching research questions: 1) What is it like to experience ppOCD? 2) What is it like to seek help for ppOCD?

D. **Sampling and Recruitment**

I used purposive sampling methods for this study. Participants were eligible to participate in the study if they: 1) were adults (18+), 2) self-identified as female 3) self-identified

as a mother, 4) had been previously diagnosed with OCD, and 5) experienced new or worsening OCD symptoms during the postpartum period.

1. **Participants**

Participants (N=6) were screened and subsequently enrolled in the study from March 2019 to February 2020. Every mother who was screened met the eligibility criteria for participation, and all mothers who contacted me voluntarily participated. Study participants were all white women between the ages of 32 and 39. All mothers were currently coupled with the father of their children. Participants had one to three children at the time of the initial interview, and each mother had experienced the onset of ppOCD symptoms from between 12 months to 36 months prior to the initial interview. One participant had been previously diagnosed with OCD during her adolescence, while the remainder of the participants were newly diagnosed with OCD during the postpartum period.

2. **Recruitment**

Beginning in March of 2019, study fliers (Appendix A) were displayed at six Chicagoland-area mental health clinics that provided specialized treatment for anxiety disorders and/or OCD. Additionally, study fliers were displayed at a UIC health clinic serving perinatal women. I identified clinics/directors to approach about the study by consulting with members of my professional network. From March to September 2019, three participants were screened and subsequently enrolled in the study. Two participants had viewed the study flier in a common area at the clinic location where they were receiving mental health services. Another mother had learned of the study from her psychotherapist and contacted me via email. Each mother completed a pre-interview eligibility phone screening, agreed to participate in the study, and scheduled an in-person interview.

In January 2019, I electronically posted the study flier on the social media platform Facebook, which resulted in the screening and subsequent enrollment of three additional

participants in February 2020. Two mothers had seen the study flier on Facebook and contacted me via Facebook Messenger to express their interest in the study. Both mothers were previously known to me, though I did not communicate with them regularly prior to the study and was previously unaware of their ppOCD diagnoses. Another participant learned of the study from her mental health service provider and contacted me via text message. Each mother completed a pre-interview eligibility phone screening (Appendix B), agreed to participate in the study, and scheduled an in-person interview.

E. Data Collection

Data were collected from April 2019 and December 2020. Six formal interview transcripts and detailed content notes from five member-checking phone-calls were analyzed. I collected contextual data in the form of both field notes (observational data, early impressions of interview themes, etc.) and field memos (personal reflections) at each major interaction/point of data collection: initial outreach and screening; formal interview; and follow-up phone conversation.

I maintained prolonged engagement with the study participants throughout the course of the research. Due to the sensitive nature of the research, I took care to ensure that participants felt comfortable with the study, as well as with me as the interviewer/researcher. As such, I encouraged participants to contact me, if they felt so inclined, with any questions or comments related to the study and/or their ppOCD experience. In addition to three formal interaction points, I had additional, participant-initiated interactions with some (but not all) of the study participants via email and text. For example, one participant sent me a detailed email describing her ppOCD experience, after her in-person interview, because she felt she could express herself more clearly in writing. Others provided links, books, and other resources they had found to be helpful, or asked informal questions about the study's progress. The nature and context of

informal interactions were considered during the process of data interpretation. The following subsections describe the three formal interaction points and associated data collection methods.

1. **Initial Outreach and Screening**

Participants contacted me by phone or email after learning of the study. I subsequently conducted an initial screening interview by phone with each participant to determine eligibility for participation. During this initial discussion, I outlined the eligibility criteria and study aims, described the procedures, and discussed the potential risks (i.e., the possibility of emotional distress when recounting their experiences). I also disclosed my own ppOCD diagnosis in the context describing motivations for developing the research. At this point, some participants began describing aspects of their own experience with ppOCD, as well as their motivation for wanting to participate (e.g., raising awareness of ppOCD; an opportunity to reflect on their experiences, etc.). Following the screening phone calls, I created field notes to document my observations and memos for additional reflections, which I employed during data analyses.

2. **Formal Interviews**

The in-person interviews were conducted between April 2019 and February 2020. Participants chose the interview location: Four participants were interviewed in their homes, one participant was interviewed at a coffee shop, and one participant was interviewed at my professional office located in the western suburbs. With all participants, I obtained written informed consent (Appendix C) prior to commencing the interview process. Interviews were audio-recorded and ranged from 47 minutes to 120 minutes in length.

Interviews were conducted in an informal, unstructured, conversational manner. Speaking of phenomenological interviewing, Taylor (2013) states, "The experience is to be told, as it is lived, so it needs to come from a spontaneous source, as a free-flowing account, with little or no rehearsals or self-editing" (p.88). Each audio-recorded interview began with a broad invitation for participants to discuss their experiences with ppOCD. This non-directive approach

allowed the participants to control the flow and trajectory of their narrative account. Some choose to discuss their experiences chronologically, while others moved back and forth in time. Prior to the interviews, I prepared a semi-structured interview guide (Appendix D) to ensure that I collected enough data for interpretation purposes and referred to the questions on the interview guide to ensure a more robust narrative from the participant. Topical areas reflected in the interview guide questions were shared as they naturally arose in conversation. Following the in-person interview, I transcribed recorded audio verbatim. Interview transcripts were my primary source of data for interpretation.

3. Follow-up Phone Calls/Member Check

The follow-up phone calls occurred between six and ten months after the in-person interview, were semi-structured, and ranged from 15 minutes to 47 minutes in length. Each call began with a discussion of the participant's feedback and ideas about the found poem I had created from their interview transcript. As the conversation progressed, we discussed our ideas about various interview themes.

To the extent possible, I made an attempt to let the participant direct the conversation. During the calls, I wrote down participant quotations that I perceived as salient in my field journal. I also recorded observations or facts relevant to understanding each mother's experience in the context of her changing lifeworld. For example, two mothers had birthed children in the time between the initial interview and the follow-up conversation. With both mothers, moving through the newborn phase once again had brought new meaning to their previous experience with ppOCD. Notes from the follow-up conversation were referenced and reflected upon during the process of data analysis.

F. Data Analysis

1. Found Poetry

The initial outcome of the first round of the data analysis was six found poems (see Appendix E); pieces of poetry which I constructed entirely from verbatim words and phrases found in each participant's interview transcript. Found poems "take existing texts and refashion them, reorder them, and present them as poems", and have been likened to a literary collage (poets.org, n.d.). Found poems served as a reflection of my initial interpretation of each mother's individual experience.

As part of the interpretation process, a found poem was constructed from each individual participant's interview transcript. Mothers who participated in the follow-up conversation later received their individual found poem prior to the phone conversation, wherein they were invited to discuss their reactions and reflections. Found poems were intentionally created as an attempt to reflect the "essence" of the each participant's experience, as I understood it at that point in time. In the following passage, van Manen (1997) discusses the phenomenological concept of essence:

> The term 'essence' may be understood as a linguistic construction, a description of a phenomenon. A good description that constitutes the essence of something is construed so that the structure of a lived experience is revealed to us in such a fashion that we are now able to grasp the nature and significance of this experience in a hitherto unseen way (p.39).

My primary purpose for using found poetry in this dissertation research was to provide the participants with an evocative interpretation of their narratives, to provide a starting point for further knowledge generation and collaborative meaning-making. Further, through the use of found poetry, I aimed to convey the voice of the participant, as I heard it, while highlighting her unique experience of being-in-the-world (Heidigger, 1962).

During member-checks, I elicited participants' reactions to found poems, which launched the trajectory of the follow-up conversation. Broadly, participants experienced the poems as representative of their unique experience with ppOCD, as well as "powerful" in an emotional

sense. Some participants referenced a particular part of the found poem during the conversation, which provided an organic opportunity for me to share why I had chosen to highlight that aspect of her experience, and thus provided an opportunity for co-creation of meaning. These conversations were utilized as contextual data during data analysis.

2. **Interpretation Theory**

The data analysis process was informed by Paul Ricoeur's Interpretation Theory (1976). Interpretation Theory is a collection of ideas, argued by Ricoeur in four essays that discuss a hermeneutical-phenomenological approach to textual analysis. Heavily informed by Heidegger's (1962) phenomenology and Gadamer's hermeneutics, interpretation theory is commonly utilized by qualitative researchers as a method of data interpretation in hermeneutical [interpretive] phenomenological studies (Singsuriya, 2015; Tan et al., 2009; Wiklund et al., 2002). In this section, I outline my process of data interpretation with reference to three levels of analysis (Explanation; Naïve understanding; In-depth understanding) drawn from Interpretation Theory and informed by an analytical process described by Tan and colleagues (2009).

Explanation. According to Ricoeur, interpreting text, which may be understood as "discourse fixed in writing", first involves a distancing from the text, a process known as distanciation (Ricoeur, 1981, p.145). Here, the primary objective is to figure out what the internal structure of the text "says" without application of the speaker's intention, nor the interpreter's preexisting knowledge and understandings (Ricoeur, 1981).

To begin, I read each entire transcript multiple times over the course of several weeks, to familiarize myself with the 'world of the text' (Ricoeur, 1981). During these initial readings, I focused on the structure of the transcript, eschewing the context of the interview and my preunderstandings to the extent possible. After reading each transcript at least twice, I began to underline words, phrases, and passages of text that were emerging as meaningful within the text (Tan et al., 2009). I then began coding the data using exploratory holistic coding methods.

Holistic coding "applies a single code to each large unit of data in the corpus to capture a sense of the overall contents and the categories that may develop" (Saldaña, 2013, p.141). One to five holistic codes were applied to each page of interview transcripts.

To keep the participant's voice central in the analysis, many holistic codes were also in-vivo codes. In-vivo coding uses the speaker's exact language to form the code, which may be generated from multiple textual elements including metaphors, ironic language, action verbs, or emphasized words or phrases (Saldaña, 2013). Codes generated during this phase included descriptions of emotional experience (e.g., "Terrified"); references to an idea or process (e.g., "Going crazy") and metaphors and imagery (e.g., [OCD is] "lurking like a shadow").

Naïve understanding. In this part of the analysis, the text returns to 'live' communication, and the analytic question shifts from 'what does the text say?' to 'what does the text talk about?' (Ricoeur, 1981). At this level, the world of the text, the speaker, and the interviewer begin to intersect (Tan et al., 2009). At this point, I again read through the transcripts, considering my own experience with the interview, my interactions with the participant, and my ideas about the participant's intended meaning. During this process, I paid careful attention to my practice of reflexivity, frequently logging my emerging interpretive ideas and engaging in reflective journaling about how those ideas had developed. Here, broad thematic elements emerged and developed (e.g., the experience of shame).

In-depth understanding. In-depth understanding involves a process of moving back and forth from explanation to understanding to continually find new meaning (Tan et al., 2009). At this point, the interviewer's knowledge about the phenomenon and life experiences are integrated into the interpretation process. Here, I applied ideas from the study's conceptual framework, the Network Episode Model (Pescosolido, 1991), as well as my own lived experience, into the process of interpretation. Within this analytic stage, I continued to identify and restructure themes and subthemes. Here, I used eclectic coding methods, although the majority of codes developed were in-vivo codes, as part of my conscious effort to highlight the

mothers' spoken words in relation to her experience. While engaged at this analytic level, I constructed the aforementioned found poems using verbatim words and phrases from each mother's interview transcript to reflect my current understanding of her lived experience.

G. Data Analysis Process

The process of data analysis was dynamic and ongoing from the point of interview data collection to the completion of the study. Following initial in-depth interviews, I transcribed each participant's interview verbatim and checked the transcripts for accuracy. All coding procedures were completed by hand. To facilitate the analysis process, I printed out two de-identified copies of each participant's interview transcript; one was kept blank, the other I marked with highlighter and pen. I kept the blank copy for reference whenever I needed to return to the transcript in its unmarked form. In-vivo and other holistic codes were written in the margins of the marked copies. In addition, I created a running list of in-vivo codes, drawn from each participant's de-identified interview transcript. Compiled in-vivo code lists were stored as separate Microsoft Word computer files, and ranged from three to six single-spaced pages. All electronic documents were de-identified and stored on my password-protected computer, while all printed and handwritten field notes were organized in binders and stored in a file cabinet inside my home office.

H. Trustworthiness and Rigor

The quality of a qualitative study may be assessed, in part, by its rigor, or trustworthiness (Lincoln & Guba, 1985). As previously discussed, in qualitative research, elements of the researcher's background, lived experience, and interactions with study participants are expected to shape the process of interpretation. As such, varied interpretations will result from one researcher to another, or even within the same researcher at two different periods in time (Koch, 2006). While another researcher cannot judge the "accuracy" of the interpretation, they should be able to understand the process by which analytic decisions were

made. Padgett (2008) states, "a trustworthy study is one that is carried out fairly and ethically and whose findings represent as closely as possible the experiences of the respondents" (p.184).

A decision trail, which transparently documents the researcher's process of methodological and analytic decision-making throughout the study, is regarded as an important measure to enhance the rigor of qualitative studies (Koch, 2006; Padgett, 2008). For this dissertation study, I created a document that served as both a research diary and a decision trail, where I recorded personal reflections and analytic research memos in the same space. Throughout the research process, I kept dated memos in a running Microsoft Word document titled "Integrated Analytic Memos". I labeled memos as *personal reflection*, *code/theme*, or *process* memos according to content: *Personal reflections* typically took the form of reflexive questions and reflective journal entries related to my own emotional reactions, ideas, or biases that emerged throughout the research process. *Code/theme* memos referred to any entry related to an emerging or existing code or theme. Finally, *Process* memos documented reflections and observations relating to any aspect of the research process—including data collection, data interpretation, and ethical considerations. Within these memos, I documented major methodological and analytical research decisions as well as the context of the decision-making. I later revisited previous memos and entered comments on how my ideas had developed or shifted since writing the original memo. This practice resulted in a transparent, reflexive log of research decisions.

Member-checking refers to a process of going back to study participants to present and discuss preliminary findings (Padgett, 2008). To initiate this process, I shared the found poem I created from the interview transcript with individual participants, and invited them to engage in a dialogue about the emerging individual and collective findings. The process of sharing a part of my interpretive work with the participants, and hearing their ideas and insights, helped ensure that my interpretation was aligned with the way in which the participants experienced the

phenomenon. It should be noted that one participant did not respond to the initial email communication to schedule the follow-up conversation. After consulting with a committee member, I sent a final email invitation to participate after two weeks had passed. I did not receive a response and did not contact her further.

Finally, I engaged in a continuous process of peer debriefing with two members of my dissertation committee who are experienced and competent in the theory and practice of qualitative research. Peer debriefing enhances the study's rigor by helping to keep the researcher honest and accountable for research decisions (Padgett, 2008). Via more than 20 phone and video meetings, we discussed my evolving ideas about the research process, preliminary findings, as well as methodological, analytical, and ethical considerations.

I. **Ethical Considerations**

This dissertation study was approved by the University of Illinois Chicago's Institutional Review Board (APPENDIX F). I obtained written informed consent from all study participants prior to the in-person interviews. I explained to all participants that a risk associated with the research included the possibility of experiencing emotional distress, given the personal and sensitive nature of the subject matter we would be exploring. To mitigate this risk, I prepared an (IRB-approved) emotional distress protocol (APPENDIX G). I also created a list of mental health/postpartum health providers and resources to be made available to participants if indicated. I made efforts to ensure that participants felt comfortable and empowered in telling their story. Before commencing each interview, I ensured that each mother fully understood the voluntary nature of research, and I explained to participants before the beginning of each interview that they could choose to end or pause the interview at any point, for any reason. I expressed gratitude to participants for their willingness to participate in the study and gave each mother a $35.00 Amazon gift card as incentive. I made the decision to issue the gift card prior to commencing the interview, so the participants understood that receiving the incentive was not

contingent on completing the interview. Further, I ensured that the participant understood that she was in control of the aspects of her experience to be discussed; it was *her* story, and she could decide which parts of her experience she wanted to bring into the discourse.

I explained to participants during the screening process and during the formal interview that I would be contacting them at a later date to invite them to participate in a follow-up phone conversation. Several months after the formal interview had taken place, I sent an email to each participant inviting them to schedule a follow-up. In this email, I explained that if they agreed, I would send a document containing re-structured verbatim words and phrases they spoke during the interview to represent a working interpretation of their experience (i.e., found poems) to be discussed in the follow-up. Padgett (2008) cautions of member-checks that some participants "may not wish to revisit their earlier statements of emotions" (p.190). Recognizing the possibility that participants might be in a very different place mentally and emotionally than when the initial interviews were conducted, I made the decision to implement this two-step process in order to give the participant an opportunity to decline to receive the found poem. At each formal interaction point, participants were encouraged to contact me, if they felt so inclined, by phone or email should they have any questions or feedback about any element of the research process/procedures.

J. <u>Summary</u>

I used an interpretive phenomenological research design to pursue a deeper understanding of six mothers' experiences with having and seeking help for postpartum OCD. Data collected in the form of in-depth interviews, field observations, and member-checking phone calls were analyzed using an interpretive process developed from Ricoeur's interpretation theory (1981). A process of continual reflexive, introspective reflection, as well as analytic memo-writing, functioned to illuminate internal and external factors that shaped the interpretation process, and thus, the study's findings.

IV.   FINDINGS

This study aimed to gain an in-depth understanding of mothers' lived experience with postpartum OCD (ppOCD), with special attention to their experiences with help-seeking. The findings presented here were developed from 17 verbal conversations with the study participants: six initial screening phone calls; six formal in-person interviews; and five telephone follow-ups. Screening phone calls and formal in-person interviews were conducted between April 2019 and February 2020, prior to the beginning of the COVID-19 pandemic. Follow-up discussions occurred via telephone between January 2020 and December 2020, between six and ten months following the initial interview.

The formal in-person interview transcripts, as well as verbatim quotations from follow-up discussions, served as primary data, while field notes and memos collected from all formal and informal interactions with the participants were considered contextually during the in-depth analysis phase of interpretation (Ricoeur, 1981; Tan et al., 2009). This chapter begins with a brief description of the sample of mothers with regard to demographic and clinical characteristics. Next, findings are presented as four overarching experiential themes, with two subthemes per each broader theme.

A. Description of the Sample

At the time of the in-person interviews, participants were between the ages 32 to 39 years old and self-identified as white, heterosexual, and cisgender women. Mothers lived in the Chicago metropolitan area. Two mothers had full-time professional careers that required working outside of the home, while four mothers worked in the home as primary caregivers for their children. Mothers had one to three biological children, and two mothers were expecting additional children. Four mothers had experienced ppOCD after the birth of their first child, while two mothers developed symptoms following their second birth.

All mothers had been diagnosed with OCD by a mental health professional and had voluntarily engaged with professional mental health services (e.g., psychiatry and psychotherapy) during the postpartum period. Participants began to notice symptoms of ppOCD in the form intrusive thoughts within two days to several weeks, or in one case, months, after childbirth.

All mothers were in a long-term, committed relationship with their children's father, which was described in generally positive terms. Participants referred to themselves with words such as "lucky" and "fortunate" when describing their access to health care and other support. All mothers had health insurance and did not experience any significant financial barriers to receiving care.

B. <u>Experiential Themes</u>

This study aimed to gain a deep understanding of participants' experiences with having, and seeking help for, ppOCD. Each of the four overarching themes presented represent an experiential element common among all six mothers in the sample: *Perceiving a Problem: Early Internal Experiences with ppOCD*; *Secrets and Shame*; *Searching for Solutions*; and *Learning to live with OCD: Acceptance and Resilience*. Subthemes exemplify the ways in which participants experienced each broader theme, both in their everyday interactions and in the context of more formalized help-seeking.

Both individual and collective experiences are presented to highlight both the commonalities and uniqueness of mothers' journey through the postpartum period as they battled OCD. Participant quotations, embedded throughout this section, provide context for the thematic findings. All quotation marks used in this section demarcate words and phrases spoken by one or more participant. Longer quotations appear apart from the text, in italics. To protect participant confidentiality, all names are pseudonyms. Themes and subthemes encompass mothers' internal and interpersonal experiences with having, and seeking help for, ppOCD.

1. **<u>Perceiving a Problem: Early Internal Experiences with ppOCD</u>**

This is not normal/ It was crazy, crazy/ I'm maybe more than/
a little anxious/ right now/ something is/ Wrong with me… (Found poem, "Iris")

Perceiving a problem: Early internal experiences with ppOCD refers to mothers' growing

awareness and concern that they were becoming seriously mentally ill, or "going crazy", as their

ppOCD emerged and developed. Desperate for an explanation, mothers searched for the cause

of their troubling experiences. Because (for most) symptoms presented within days or weeks

following birth, mothers considered that something physiological (hormonal fluctuations, sleep

deprivation, an infected C-Section wound, etc.) could be causing their intrusive thoughts and

related fear and anxiety. Comparing their postpartum experiences with those of their family and

friends, or (for two mothers) their own previous postpartum experiences, mothers concluded

that what they were experiencing was definitely "not normal"—even in the context of the chaotic,

physically and emotionally demanding postpartum period. Two internal experiences were

highlighted—the lived experience of OCD-associated intrusive thoughts and images; and a

related sense of "losing myself" as they tried to navigate new motherhood while experiencing

the onset their OCD symptoms, experienced as terrifying and psychologically disturbing.

The Experience of Intrusive Thoughts

Mothers experienced persistent intrusive thoughts involving verbal ideas and mental

images of violence or other harm inflicted on their children and/or themselves. Intrusive thoughts

were experienced as internal — emerging from oneself, instead of originating from an external

source, as is common in postpartum psychosis, a severe, but very rare, maternal mental illness.

(PSI, 2021). Yet, thoughts and images were perceived as invasive, entirely unwanted, and

incredibly painful to endure.

Mothers tended to experience a mixture of verbal thoughts and mental images. Verbal

thoughts were experienced as the mind continuously fixating on various potential scenarios that

could cause harm to their child or themselves. These thoughts occurred repeatedly throughout

the day, but intensified greatly in situations wherein mothers identified potential danger, or were

exposed to certain sensory stimuli. Highly specific intrusive thoughts could be triggered by

current events. For example, a media story about a child's death from drowning, a televised

sexual assault trial, and reading a book in which a character experienced sexual abuse were

thought to trigger similar types of intrusive thoughts among participants. Mostly, mothers

experienced intrusive thoughts about the present or near future. However, one mother

occasionally experienced intrusive thoughts about future events.

> *There was this big* [public sexual assault] *trial, and again, my children were two and just born. But I was doing a painting, I was doing a painting for my older daughter's room, and I was just so, so, worried about them in college. Like 15 years from now—I thought* [it] *would happen to them. I remember drawing this one mountain over and over and over again, because I couldn't get the thought out of my head. And I remember thinking, if I can just make this one thing perfect, then maybe I could prevent it* (Violet)

Intrusive thoughts were perceived to burrow into mothers' brains, and were experienced as

aggressive, persistent, and relentless. These thoughts typically occurred in the form mental

intrusions of "what-if" scenarios:

> *What if I put her in the microwave?*
> *What if I stab her?*
> *What if I throw her out the window?* (Sofia)
>
> *What if I sexually abuse my baby?* (Amber)
>
> *What if she gets the flu and dies?*
> *What if I die?*
> *What if he gets paralyzed?* (Iris)
>
> *What if I kill myself?* (Gemma)
>
> *What if I put him in the sink and let the water fill up?*
> *What if I put him in the oven?* (Lark)

The experience of vivid mental images, sometimes paired with the verbal thoughts and

other times occurring on their own, generated great emotional distress, and tended to be

experienced as more disturbing than verbal thoughts alone. Mothers reported "seeing"

scenarios such as their child being afflicted by severe illness, images of themselves engaging in

violent acts toward their children or themselves, or the aftermath of those imagined situations.

Specifically, mothers experienced deeply disturbing mental images of themselves engaging in actions such as, putting their baby in washing machine, microwave, or oven; stabbing their baby with a knife; dropping their baby out of a window; drowning their baby during bath time; choking/strangling their baby, and sexually assaulting their baby. Some mothers saw images of accidental harm, such as their children drowning or choking. Another mother experienced persistent intrusive images of her own death by suicide. In the following passages, mothers describe their experiences with "seeing" visual images in their mind.

> *The first time I just saw myself, like, strangling her. And it was so real, so vivid! I looked at her, I looked at my hands, I started shaking….I remember it like it was yesterday* (Sofia)

> *I'd see the oven, for example, and I would think—oh no, what if I did this? But then there are times when I'd see myself….like maybe, doing that. And that is where it got so, so, scary! I didn't see like….ugh, this is gonna sound so terrible. But I didn't see like…a hurt baby. I just saw myself…doing an action, like going toward doing that. Or turning on the water, with the bathing, letting it fill up. Something like that. Seeing it happening, but not a hurt baby. So maybe more the action I could see in my mind. You know, you think your house is a safe place but then you start to realize….there are so many dangerous things, everywhere. What if I hurt him? Am I gonna hurt him?* (Lark)

Prior to receiving treatment, mothers experienced intrusive thoughts and/or images at least every day, sometimes nearly constantly, and sometimes with varying levels of frequency and intensity throughout the course of each day. The experience of intrusive thoughts was perceived to occur both at random and when provoked by a sensory trigger, such as seeing an object associated with violence.

> *There is this filet knife that my parents have, that cuts everything just perfectly. If he* [son] *was anywhere near me in the kitchen, I'd look at it, then I'd look at him, and then I'd see it happening* [attacking son with knife]. *And it was so scary, so overwhelming!* (Sofia)

> *I didn't want to do laundry, what if I like, you know….*[put child in the washing machine]. *It's so hard to say these things out loud!* (Lark)

Collectively, mothers primarily experienced thoughts of harm coming to their infants. However, Iris and Gemma initially experienced intrusive thoughts about their own health and

well-being. Both mothers noted that while their intrusive thought content sometimes extended to

their children:

> *It's usually not focused on the kids at all. Which, I think that is what is misleading about postpartum OCD, like I'm not necessary having intrusive thoughts about the kids, or fear of hurting them, although I was fearful of hurting them at one point, when things were really bad. But it doesn't necessary have to do with the children* (Gemma)

Iris, who primarily feared illness and accidents, experienced the focus of her obsession

with illness shifting from herself, to her child(ren), to her husband, and back to herself. The

thought of contracting a life-threatening illness generated anxiety, as did the thought of dying

and leaving her children without a mother.

> *I remember getting the stomach flu, and right away starting to google, can the stomach flu kill you? How long does a stomach flu last? How likely am I to die from a stomach flu? And I remember being like, oh my gosh—I'm gonna die. I'm gonna die! I need to know what kind of stomach flu I have—bacteria, is this food poisoning…and things like this started to happen more and more. And in retrospect I'm like yep, this is not normal!*

Intrusive thoughts were sometimes, but not always, accompanied by behavioral

compulsions in an attempt to reduce the anxiety generated by the thoughts, consistent with the

clinical profile of OCD (Blakey & Abramowitz, 2017). Notably, in this sample, self-identifiable

behavioral compulsions were experienced more frequently among mothers who primarily feared

illnesses and accidents, in contrast with those who primarily experienced thoughts of violence,

who tended to engage in compulsions less frequently and placed much less emphasis on them

in their narratives. In fact, two mothers who primarily experienced harm OCD (Lark and Sofia)

didn't recall experiencing behavioral compulsions at all. For these mothers, no physical or

mental action was perceived to have the ability to reduce the excruciating anxiety that stemmed

from their intrusive thoughts of harming their babies. However, both Lark and Sofia did describe

engaging in certain behaviors, such as avoidance behaviors, that may have been clinically

classified as compulsions, although they did not view them as such (Williams et al., 2011). In

the passage below, Lark reflects on her experience with compulsions:

> *I didn't have anything like excessive checking…I don't know…I wouldn't say this is a compulsion. But I wasn't eating, and my mom would be like, here, have a Mac and*

Cheese Lean Cuisine. So, I'd eat the same thing, every single day. And I think part of that was….I didn't want to turn the oven on to bake something, because I was going to hurt my baby with the oven. I don't know, or, I don't know if this is a compulsion but it was like, I couldn't go outside, I couldn't do very simple things. For a while. Not so much like closing a door, or washing my hands, nothing like that. So not really…I wouldn't say I was even overly…I mean I would check when he was next to us, to see if he was breathing, of course, as every mother does. But not like every three minutes. So I would say the most, the biggest, thing for me, was the intrusive thoughts. The thoughts. The thoughts. And images, too. Thoughts and images. So I didn't really have the compulsions. (Lark)

Comparatively, among mothers who primarily feared accidents or illness or other unintentional harm, compulsions manifested in the form of excessively checking their infant for symptoms of illness or harm, spending several hours per day researching the content of the intrusive thought (e.g., the symptoms of a specific illness), and, perhaps most commonly, seeking near-constant reassurance from external sources, such as family members, the internet, or presenting to the ER. Violet, who primarily experienced intrusive thoughts about accidental death of her children, and the only mother to have been diagnosed with OCD prior to the postpartum period, explains her early experiences with intrusive thoughts (obsessions) and compulsions, and how they evolved over time:

I think how I would describe OCD is like, extreme superstition. When I was younger, I was afraid something bad was going to happen to my mom. And I could soothe that thought by doing whatever task I was doing perfectly, like if I can just get this paper perfectly straight, it might make that scary thought about my mom not come true. Or if I was walking out of a room, turning off the light switch. If I had an intrusive thought—ok, well let me just try again. Let me turn that light off again, and again, just right. Now, I know how absurd that sounds! But that thought just screams louder and louder in your head until you do the compulsion to soothe the obsession. Because…you just can't get that thought of something terrible happening out of your head!

So, the focus of my OCD changed as I got older—I think it was depending on my biggest priority at the time. It turns into peer acceptance, certain dating relationships. As a junior in high school, I remember taking a multiple choice chemistry test, and I knew the right answers. But I was afraid something terrible would happen if I picked the right answers…so I was a B student getting Ds. I was a good kid in high school…two teachers pulled me aside and were like, what is wrong? What is going on?

Violet goes on to describe how the frequency and intensity of her OCD intrusive thoughts and associated compulsions seemed to dwindle as she entered adulthood and achieved a greater understanding of OCD and the way in which it affected her. While she still

experienced occasional intrusive thoughts, she didn't feel the need to succumb to the urge to engage in behavior compulsions to soothe her thoughts, and she was able to dismiss any lingering intrusive thoughts with relative ease. [As an adult] "I could block it out, it was just kind of like, noise in the background..."

> *But then my OCD came roaring back after the birth of my second child. If it was something more trivial, I could block it out. But now* [the intrusive thoughts] *are about the health and safety of your child. That is when I could not block it out. I couldn't risk it! That's why OCD is called the Devil's Disease, because the more you do it, the more you do it. The more you give into the compulsions to relieve the obsessions, the more compulsions you will have. But if you don't…you are in such distress! Could something happen?? It scares you too your core. It's like your heart is walking outside of your body, when you have children* (Violet).

In contrast, Gemma expressed an alternative perspective on the experience of the relationship between intrusive thoughts and compulsions.

> *If you were to rate, obsessions I'm like eight out of ten. Compulsions…I'm like two out of ten. I don't really find the compulsions to be that helpful in resolving anxiety. They are time-consuming and unhelpful in furthering the cycle, and I can resist them fairly easily. But I do…I have to resist checking things on the internet, like researching different diseases, or medications, or reading articles or any of that stuff. I used to go to my husband, I used to have him take me to the ER, a lot of medical reassurance-seeking. But I have to kind of, resist that stuff* (Gemma)

Whether or not participants experienced overt behavioral compulsions alongside their intrusive thoughts, exposure to the content of the intrusive thoughts, and the subsequent fear that they could come true, was universally regarded as the most horrific part of their ppOCD experience. The repeated, relentless experiences with intrusive thoughts led to the sense of living in perpetual state of fear and perceived isolation, even while living among their spouses/family in "supportive" environments.

Lost in the Dark: Postpartum Life with undiagnosed OCD

Consistent with the rudimentary clinical profile for ppOCD (Blakey & Abramowitz, 2017) five of the six mothers noticed symptom onset within days or weeks of childbirth. Intrusive thoughts led to a sense of perpetual anxiety and fear, entwined with the "normal" yet undesirable aspects of the early postpartum. *Lost in the Dark* refers to the overwhelming,

experience of navigating the challenges of the postpartum period (e.g., sleep deprivation, bodies healing from birth, hormonal fluctuations from birth and breastfeeding) while simultaneously experiencing the rapid onset of OCD intrusive thoughts. Painfully, while participants fully experienced the typical challenges and pains of the postpartum period, they experienced little to none of the typical joy that also comes with the arrival of a new baby. When mothers reflected on their early days, weeks, and months with their newborns, words and phrases such as "afraid", "terrified", "losing my mind", "going crazy" and having "a mental breakdown" were woven through their narratives.

Mothers who feared harming their children avoided interacting with them any more than was perceived to be necessary, precluding spontaneous opportunities for mother-child intimacy and bonding. Amber, who experienced intrusive thoughts of sexually harming her child, describes the pain she felt while providing basic care to her newborn son.

> *Changing diapers and giving baths was torture. I didn't want [husband] to ever leave him alone with me. I started having panic attacks…I didn't want to wipe him for too long, or anything like that. I did it, but it was so, so horrible to do…* (Amber)

Lark, who experienced intrusive thoughts of physical harm, expressed similar sentiments.

> *As soon as* [husband] *went back to work, I had my mom—like I to have her come over, or I would go to her house. Because I wanted someone with me at all times. Everything triggered me. I didn't want to put a shirt over his head, I didn't want to bathe him. I didn't want to do anything because…it almost felt like I had so much power over this person, and I could hurt him. And then it was, Am I going to hurt him? Like, is my mom gonna come over today, or where do I need to go, to protect him… from me? Not that I ever acted on those thoughts, but if I did…well, it was just terrifying…*(Lark)

In the early postpartum weeks, mothers puzzled at the meaning and origin of their symptoms. For example, Lark considered that the C-section wound was infected, and that the hypothetical infection may have been affecting her brain function, producing the intrusive thoughts.

> *So I went to the ER for like….a mental breakdown. I was not eating. I was not sleeping. I couldn't drink. I was having heart palpitations. I tried to rationalize it, like I'm crazy right now because I have an infection. I must be sick, or something else is going on. I had to blame it on something.*

Two weeks after birth, she self-presented at the ER, convinced that her brain function was being

affected (i.e., she was "going crazy") due to a physical illness. After being assessed by a social

worker and ER physician, she was discharged and did not receive further physical or mental

health treatment for an additional six weeks. Looking back, Lark recalls her experience with

presenting for help at the ER as disheartening and discouraging.

> *So when I went, they knew—they looked at me they were like, your lips are dry—they could tell I was dehydrated, everything about me just looked sick. And he* [doctor] *was like, I can give you a prescription for an antidepressant. But again, they weren't really looking at the big picture. So I didn't even take it in* [the prescription]. *I'm like, I'm not taking this, I need someone to actually understand what is going on before just being thrown on something. I don't, I don't need, like, an anti-depressant. I don't really understand all the drugs and how they work but I just…yeah, going in, you felt helpless. Like I'm gonna go here, I'm gonna go get help. No. And now I feel worse. I feel more hopeless.*

While mothers lived with the daily fear of their intrusive thoughts "coming true", also

present was an existential fear that they were losing their grip on reality, as Lark's experience

illustrates. Participants wondered, if they were experiencing postpartum depression, or even

postpartum psychosis, maternal mental health conditions with which they had more passing

familiarity. Interestingly, while it has been suggested that ppOCD is highly comorbid with

perinatal depression (Blakey & Abramowitz, 2017; Sichel et al., 1993), three of the six mothers

emphasized that they did *not* feel depressed. Among those who did experience depression, the

depressive symptoms (i.e., depressed mood, anhedonia) were perceived to occur days to

weeks after the onset of the intrusive thoughts, and were perceived to stem from their ppOCD

experiences. Mothers who were considering engaging with mental health services were

discouraged by the perception that treatment seemed to be targeted for postpartum depression.

In some cases, mothers identified how depression-specific or combination depression/anxiety

treatment/peer support acted as a deterrent to engaging with support.

> *I actually did an IOP because things were really out of control and I couldn't shake the anxiety. The IOP focused on depression and anxiety, not necessarily OCD. If I had another bad flare where I was really losing control…I don't think I'd do the same program* [again] *because a lot of it was for depression. In a group someone actually got mad at me and voiced, 'I don't think you've ever struggled with depression'. And I was like, 'No,*

I'm not saying I have. I'm not depressed. I'm really anxious!' So a lot of it focused on depression and [those] *behaviors. Like, I don't have trouble getting out of bed in the morning. I may be really anxious when I get out of bed, but I've never spent the day in bed…I'm not depressed!* (Gemma).

You don't know where things stem from. Like the postpartum stuff, where is this coming from? And is also very debilitating because….you go from this like, I was sick during pregnancy, but other than that, I felt great. You go from this super high. You know, you have the baby. Then you have these hormones, whatever, all that. And then you are like….no. This is not how I'm supposed to feel. And it's just like this huge, down. And it's so scary. And then in the beginning, the whole depression thing….and depression is a huge deal. I understand that. But I think it deters people. Ok, you [think] *you have depression. You read the things…and no, no I don't. Everyone is like, oh, you just couldn't get out of bed? And I'm like, No, no. I can get out of bed. I want to get out of bed! I want to get out of my house! I could get out of bed* (Lark)

Ok, so there are postpartum support groups for [postpartum depression]. *I avoided that because I'm like….I'm not depressed! I am NOT depressed. This is not depression. So I avoided that* (Violet)

Mothers, themselves, felt bewildered as well as misunderstood by others. It wasn't necessarily depression….but it certainly wasn't "just anxiety". Half of the mothers had received previous treatment for clinical anxiety, and recognized the presence of "severe" or "intense" anxiety in various forms: Constant worrying about the health and safety of their children and/or themselves; feeling on-edge and hypervigilant; feeling nauseas, unable to eat, or otherwise physically ill; as if they were "crawling out of my skin"; and, for several mothers, frequent episodes of panic. Collectively, all anxiety manifestations were experienced as stemming directly from the experience of intrusive thoughts and images. Participants struggled to describe their internal experiences to family and other supportive loved ones, as described by Gemma.

My husband is like…it's a nice day outside, its Saturday! How hard is it to sit on a chair at the pool? I'll do all the heavy lifting with the kids….

And it's like…I can't even explain to him, that I just…can't right now. It's very hard for other people to understand. Like, what are you so upset about? What is bothering you so much? Because it's such an imagined thing [intrusive thoughts]. *Like I don't WANT to be worried about this right now! I have other things that I need to be worried about, things that are real* (Gemma)

Mothers assumed a certain degree of anxiety was "normal-for-postpartum", brought on by the

physical and emotional demands of the postpartum period as well as natural worries about the

child's well-being. However, based on previous experience or observations of peers during the

postpartum period, mothers quickly concluded that their anxiety experiences surpassed the

boundaries of normal postpartum anxiety, or "normal" clinically significant generalized anxiety.

Participants silently compared their own mental state and postpartum experiences with those of

other mothers in their social network, both naturally and intentionally.

> *I know so many women who struggle with anxiety…it's like an epidemic! Especially women in their 30s, with young children at home, working or not working, just busy women. They have a lot of anxiety! But one thing I've noticed—I felt like mine was worse, or special, or different…"* (Gemma)

> *I think when you think it's just anxiety, and you hear other people's anxiety experiences, and they don't match up with yours at all you think….maybe something REALLY is wrong with me.* (Amber)

Several weeks to months postpartum, prior to receiving a correct diagnosis and

appropriate treatment, mothers transitioned into an autopilot-like state of detachment as they

went about their days. Often, this in-between period was marked by feelings of dissociation and

isolation, and later, recalled with a heavy sense of loss. In a sense, participants became

accustomed to their intrusive thoughts and associated anxiety and fear. They still felt terrible,

but they were learning how to function in a state of fear. However, a sense of slipping further

and further out of one's own mind was continually experienced. Mothers were in agony over

their perception of themselves, which vacillated from "bad mother" to insane.

Lark reflects,

> *You don't know yourself anymore, you're not who you've always been….you lost who you were….You see those people in the media* [mothers who have killed their children] *You think that's gonna be you. You think, I guess I'm just one of those people who is not wired right…and I'm just now finding out about it* (Lark)

Some mothers had to go through several mental health providers before receiving an

accurate diagnosis and the most efficacious help. While participants experienced some benefit

in working with providers who helped with general anxiety management, they did not experience

significant symptom relief until they encountered a provider who "understood OCD" and was able to provide more targeted treatment and support.

> *Because it wasn't just anxiety, the OCD never really went away…it just became more manageable I guess. I had a list of things I could do every day…meditating, drinking lots of water, working out 7 days a week. But I was just kind of… managing it. It was still horrible, but I was used to it at that point.* (Amber)

In between managing their new normal, mothers described experiencing "flares" or "waves", where their OCD felt intensified, supercharged— an especially intense period of particularly persistent intrusive thoughts, often accompanied by episodes of panic, severe anxiety, lifestyle changes, and feelings of physical illness. Several mothers described experiencing panic and extreme fear while trapped in a wave of intrusive thoughts. While engulfed in a wave or flare, mothers described felt completely controlled by their intrusive thoughts; they felt overpowered and absorbed by them. For mothers who experienced compulsions in response to their thoughts, the need to engage in compulsions was perceived to increase, as well as the time spent engaged with compulsions. Flares/waves were typically described as lasting a couple days to several weeks, or occasionally, longer.

> *If I'm in the middle of an episode that's been a couple weeks that is not relenting, it can kind of feel like, I just don't want to live like this. And, um, it can feel very exhausting, and like I can't do this anymore, this is too hard* (Gemma)

Emotional and physiological stressors experienced throughout the first days, weeks, and even months postpartum tended to exacerbate the perceived intensity of ppOCD intrusive thoughts and set off "flares". For example, Iris recalls experiencing a major exacerbation of her intrusive thoughts, panic attacks, and overall emotional distress while she was being considered for a promotion at her job.

> *I was like, on an interview every single second of the day at work. I didn't want to exercise, because I was afraid I'd go into cardiac arrest. It got to the point where I didn't want to take the kids places, because I was scared of panic attacks, and what if something happens to me and I can't take care of the kids? And that's the point it became like, ok, I actually can't function like this, this is really bad, I was losing all this weight because I couldn't eat, I wasn't suicidal, but I was like oh…this is how people become suicidal with mental health* [issues]. *Because you cannot live like this, you cannot live this way* (Iris)

Amber, who began a process of in-vitro fertilization (IVF) several months after birthing

her first child, describes the way in which her OCD symptoms intensified with the introduction of

the hormones combined with other life stressors.

> *We started IVF and soon after I started the hormones, my thoughts came on stronger. That cycle ended in a fail, and I was now depressed from that and from fighting the thoughts for so long. I was overwhelmed with grief and exhausted from fighting the thoughts. At that time we were under a lot of stress…I wasn't getting pregnant, I lost both of my grandmas. The minute I started the treatments….the hormones, I could tell, they were making a difference. I mean, they make a difference no matter what, no one does well with external hormones! But day three after starting the hormones, I started having panic attacks.* [*The thoughts*] *made my anxiety more intense. I had been reading a book and in the book a girl was sexually abused by her dad and I thought, 'what if I'm capable of that?' I couldn't stop checking my brain for signs of being a sexual abuser….I remember being in a department store parking lot and a car was backing out and I thought—what if this car hits me? Then it can all be over. And I thought, this is NOT good. So I called my doctor and we ended up going to urgent care.*

Gemma also described an exacerbation of her ppOCD symptoms following a period of stress

and hormonal change—in her case, brought on by discontinuing breastfeeding.

> *Not every stressful event sets off a flare, but* [OCD] *is tricking me all the time. All my major flares have been in times of transition and there have been two that have been really closely linked to the time I weaned from nursing. So in this last flare-up, this last episode [son] was about 9 months. I had just weaned from the pump at work, so it was a major hormone shift.*

Although mothers all considered themselves to be in an improved mental state at the

time of the interview compared with their darker days postpartum, they expressed a sense of

loss, a sense of regret about the manner in which the first weeks and months of their infants'

lives were experienced.

> *I don't think—I don't think it* [ppOCD] *affected my ability to care for my child, but I wasn't enjoying it in a way I should have been. I wasn't present when I needed to be present, I wasn't getting rest because I was checking on her 18 times a night…. And it just really overshadowed what should have been a happy time…I was not happy. I was in survival mode. Just surviving.* (Violet)

> *With* [son] *I feel robbed of that first month, those first two months, with my child. Because—the whole time I was not thinking about, this is my first child, I can just sit here, skin-to-skin, sit on the couch, enjoy these moments because they go by so quickly. Instead, I was worrying about how I was going to survive it.* (Lark)

2. <u>**Secrets and Shame**</u>

OCD is/ more intense than/ anxiety/
The thought screams louder/There is an element of shame (From Found Poem, "Violet")

Accompanying the fear and anxiety was a deep sense of shame. Participants felt as though they were unworthy or uncapable mothers. They felt isolated, misunderstood, and supremely helpless against the onslaught of their intrusive thoughts. Mothers perceived their symptoms as embarrassing, humiliating, or worst of all, an indication that they were dangerous or deranged. Over time, participants came to understand that it would become necessary to more fully disclose their experiences, if they wanted to get help, but they felt fearful and ashamed.

Shame and Fear in Symptom Disclosure

Most mothers experienced great reluctance to disclose the content of their intrusive thoughts to both members of their informal support network (spouses, family, friends) and their formal support providers (Physical and mental health providers). While most participants did disclose some aspect of their experience to individuals within their support network, they generally did so with caution, speaking broadly and vaguely about their internal experiences and omitting details about the specific content of their intrusive thoughts.

For example, mothers told family members that they were "not feeling right" (Lark), or "having some scary thoughts" (Violet), or that they were just "really anxious" (Gemma). Mothers found it difficult to verbally articulate their experiences with ppOCD, particularly the content of their intrusive thoughts, although they sometimes felt the desire to do so. Feelings of shame around symptoms disclosure were closely connected with feelings of fear. With their spouses and other loved ones, the primary fear was that their closest supports would regard them as "crazy" or become afraid of the woman—or the mother—they had now become in the wake of ppOCD.

I was afraid. I didn't know what OCD was and wasn't. Until I read up on the specific type of OCD. But back then I didn't know what it was. I just said, 'anxiety attacks, I can't

relax'. I didn't mention anything about the sexual parts. Like with my dad, I didn't say, 'Hey, I'm having these scary sexual thoughts' [laughter]. *I think it was more like, 'I think I'm going crazy, I'm afraid'. But I just told my dad and my husband. And a little bit my friend. My best friend. But even then, it was just very, very slowly* (Amber)

I didn't want to say it [intrusive thought content]. *I didn't really give details. Even to my husband. I just told him—my brain feels off, I don't feel right, all this stuff. It's just—it's just so hard to say these things out loud, you know? Because of just… how sick they make you. Like, who thinks like this?* (Lark)

Notably, despite their fears, mothers felt generally supported by their loved ones, both before and after full symptom disclosure. This perception of support and understanding from partners and other loved ones was invaluable in emboldening mothers to further their help-seeking efforts. Lark continues,

My husband, even just telling him, I don't feel right in the head, he's like, we gotta get you in, here, take this insurance card. There was no judgment there. My mom, I told her, I was just like mom—I feel uncomfortable being alone, I would say things like that, where they understood that something was going on. But what it was, they didn't really know.

Once they had accessed formal health systems, mothers (and their loved ones) grappled with the decision of whether or not to take the perceived risk of disclosing the content of their intrusive thoughts to health providers. Mothers understood the importance of being honest with providers in order to get the most effective help, but were afraid of losing their children (i.e., they were afraid they would be involuntarily hospitalized and subsequently deemed unfit). This fear was especially intense if the mother predominantly experienced thoughts of violence. In the passages below, Lark recalls a conversation with the hospital social worker after she had self-presented to the ER; a conversation with an outpatient therapist several weeks later; and finally, a conversation with psychiatrist two months postpartum:

The social worker comes in, she's like reading through this list of things. She's like, 'do you feel depressed?' No, I don't feel dep—I couldn't find a way to describe it. 'Do you want to hurt yourself? No, never had that thought. No, I don't. 'Do you want to hurt your baby?' And in that moment, I just said 'no' because I thought, If I tell them I'm having thoughts of harming my baby, they are going to take my baby away!

After several appointments with an outpatient therapist who specialized in working with postpartum women, Lark could still not bring herself to disclose the content of her violent

intrusive thoughts. As a result, she did not receive the type of help she was hoping for and

needed.

> *I think she* [therapist] *was just treating me like it was anxiety and depression. When I started mentioning 'weird thoughts' she was like oh, you should see a psychiatrist, you might need some medication. But even with her, I was scared she was going to like, report me.*

It was not until meeting with her psychiatrist for the first time, two months after the onset of

symptoms, that Lark decided to disclose her intrusive thought content.

> *I went to him* [psychiatrist]*, you know, kind of nervous again. Like, I know I'm supposed to be open with you so you can help me and treat me. But I'm worried you're gonna take my kid away from me if I do…just because of the kind of thoughts and the things I'm saying. So I started to talk a little bit, and then he pretty much said what I was thinking and feeling. And I said, yes! That's it! He had a very good demeanor to him. There was no—he wasn't freaked out, it was seriously the biggest feeling of relief to be like you understand what I'm* going *through, and you're not going to put me in a mental institution. I'm not saying the Dr. is your friend. But it's kind of like a good friend. Just being there for someone…* (Lark)

Other mothers also expressed relief when they came across a mental health provider who

appeared to both recognize and understand ppOCD.

> *My very first appt with* [therapist]*. Oh my God! It was so wonderful. When I told her what was going on, she was like, yeah…you see yourself doing this, you see yourself doing that. A lot of moms do this, a lot of moms do that and she told me all that, and what it was, and I was just like, ahhh! Thank you! It's not just me. I'm not a freak* (Sofia)

In contrast, participants felt frustrated when they *did* exercise vulnerability in disclosing the full

extent of their symptoms, and the presence of OCD went unrecognized, or at least untreated, by

their providers.

> *I look back on all the things I would tell her* [former therapist]*, and she never really picked up on the fact that it was OCD. I told her everything. She kinda just picked up on that it was anxiety. And it's not treated the same way* (Amber)

Notably, there was one participant, Sofia, discussed her experiences openly with family

and health providers from the first onset of her postpartum symptoms. Sofia was very vocal in

disclosing the content of her violent intrusive thoughts, which she called "visions". While she

was conscious of the potentially stigmatizing nature of her thoughts, Sofia discussed how the

intense anger she felt toward the experience of her visions overpowered any feelings of shame

or fear in disclosing them.

> *I felt….hate. Hate describes everything. I would become very angry about it* [the experience of intrusive thoughts]. *I'm a very proactive person. I knew there was a stigma, but I was ok with it. The stigma is lifted because someone comes out about it. I don't like to keeping things inside, I gotta get it out. I don't want it, I don't want it* (Sofia)

Stereotypes and Stigma

Days after giving birth, Sofia recalled having a conversation with her mother after she told her

midwife and her mother that she had seen images of herself strangling her then five-day-old

daughter.

> *I called my midwife and she said if I'm having thoughts of hurting her I need to go to the ER. Mom—should we go to the ER? What if I hurt [daughter]? And she's like, "no, I don't think you need to. Do you realize if we go to the ER they are going to admit you to the psych ward? And you're not going to be able to nurse, or do anything, and she might be taken away from you?"*
>
> *And I'm like….what?*
>
> *She said, "Just stay out here, if you need me, I'm here. I know you aren't going to do anything, you just haven't slept in 5 days. This is your first baby—you'll be fine"* (Sofia)

Although Sofia was comfortable disclosing her intrusive thought content and presenting

to the ER, her mother was fearful of her grandchild being taken away if her daughter sought

emergency care. Following her mother's advice, Sofia did not present to the ER that evening,

but did receive help via a self-initiated process outpatient within days of this event.

Similarly, Amber describes an event wherein she and her husband were driving to the ER, but

decided to turn back.

> *There was this one time when it was really bad, and I just wanted to be checked into the hospital, like I want help. And we were actually on our way to [hospital], and I got a call from my therapist, I called her—she called me back, we just kind of talked. And I think my husband was just kind of resistant about taking that step, like going to [behavioral health hospital]. And I didn't end up going. I almost feel like when you go to* [hospital]*, your crossing a line as far as your crazy level goes. And I think he felt that too. It doesn't feel like getting help. Because of all the stigma and stuff that goes with it* (Amber)

In addition to perceiving stigma about postpartum mental illness, or mental illness

broadly, mothers often mentioned or alluded to stereotypes and misconceptions commonly held

about OCD, specifically. For this reason, participants tended not to speak openly about their

OCD with family and friends. Violet shared her perceptions on stigma associated with OCD

versus "Anxiety".

> *I told my best friend I was meeting you [for study]. And she was like….what? I never knew you had postpartum OCD! And I was like yeah* [sigh]. *Because OCD is just so…I don't know, you almost feel like you're some sort of sorceress or something. It's just weird. Anxiety? Anxiety is almost trendy, sexy, right now. Oh yeah—I wrote an article about anxiety, it got published on a big platform, I shared it on social media, that I had no shame with. But there is an element of shame with OCD. It's more….complex.*

Having an inaccurate or incomplete conceptualization of OCD, especially, often

precluded being able to self-identify OCD symptoms before receiving a diagnosis from a

provider. Prior to diagnosis, mothers' mental representations of OCD were of stereotypes

perpetuated through social media, which often portray OCD as trivial, overly simplistic, and/or a

comedic joke (Palveko & Myrick, 2015). Stereotypes featuring contamination OCD and

individuals engaged in repetitive motions were not congruous with their own experience of

intrusive thoughts and associated compulsions. While they entertained the possibility of

postpartum psychosis, which is far less common, it never occurred to participants that they

might be experiencing OCD — postpartum or otherwise.

> *It was pretty quickly after I started [behavioral health program] that they were like, this is OCD. This is classic OCD. But I was like, I'm not—I'm not like a germaphobe, I'm not like into all the contamination stuff, and they were like, yeah that's not what it is about at all* (Gemma)

> *When* [therapist] *told me I had postpartum OCD I was like.....what? Because you hear of OCD, you see OCD, and you think its like—before I leave a room, I have to go like this* [makes motion] *15 times. And it's got nothing to do with it* (Sofia)

> *Being clean is not like, necessarily, I mean I'm sure some people obsess about that. But there is so much more to it…but I didn't know!* (Lark)

> *People always use 'OCD' or obsessive as like, a cute word….I mean, I'm not about cleaning or some of the stereotypes you see with OCD* (Iris)

Health providers who were not well-informed or vocal about OCD were perceived as

less-than-clinically-effective, at best, and stigmatizing, at worst. Amber describes an experience

of deeply felt shame while engaging with a psychotherapist who specialized in the psychological treatment of women during the postpartum period.

> *The first therapist I saw was awful. She wouldn't let me get a sentence out without diagnosing me. I mean, she threw out words like 'fetish' and 'repressed trauma'. it was j ust bad. She had no idea what OCD was at all, you could just tell. It was very discouraging, and she was the only* [*postpartum*] *therapist* [hospital system] *had* (Amber).

After receiving a diagnosis and coming to understand OCD, mothers also began to have stigmatizing experiences concerning the colloquial use of the term "OCD" in popular culture and among peers and family. This seemingly innocuous common practice led to mothers feeling misunderstood, both at an interpersonal and societal level.

> *My family, you know, we are very sarcastic, we goof around. But I think it's a sensitive thing for me. So when I hear that they* [family] *is 'OC', or when you see someone on Instagram and they're like, I'm so OCD with my…this and that. I'm like….you have no idea! People think it's a joke. And like my dad or someone will say it and it's like, now I get it. It is NOT funny* (Lark)

> *It never really bothers me when people say, 'I'm so OCD'. But there is a distinction. The distinction with true OCD is that you are truly struggling, you are truly suffering. You feel like something catastrophic is going to happen if you don't give in to the compulsion* (Violet)

Mothers felt the greatest degree of shame and internalized stigma prior to receive a diagnosis, when they believed they were losing their sanity, and feared that the removal of the children due to the very real (in their mind) possibility that they were "crazy", unfit mothers. While feelings of shame did not disappear entirely after obtaining a ppOCD diagnosis, mothers continued to feel misunderstood by providers and loved ones, which spurred a further need to become as educated as possible on every element of their mental illness.

3. <u>Searching for Solutions</u>

> *I was educating myself/ I had to keep educating everybody/ I saw so many people/ I just wanted to get/ through it* (From Found Poem, "Sofia")

The theme *Searching for Solutions* refers to mothers' self-propelled, persistent pursuit to find "answers" and support for their ppOCD. Mothers searched for resources in multiple spaces — both physical and virtual. While participants were not decidedly sure of what "type" of help

they needed, they were certain about one thing: They wanted relief from their symptoms — and quickly. Mothers initially presented for help at urgent care centers/hospital emergency rooms, or presented to their midwives, ob/gyns, or primary care providers. During these initial encounters, mothers felt they were in crisis, and lacked awareness about ppOCD. They weren't exactly sure what they were experiencing; they just knew that something was wrong. This was even true for Violet, who had been previously experienced symptoms of generalized anxiety as well as clinically significant OCD as an adolescent.

> *Anxiety has been a shadow lurking in my life since I was 11 years old. It comes and goes. But OCD is very sneaky. It took me a bit of time to recognize it* [postpartum]. *I don't think it was on my own — it was with my therapist. Probably within 6 to 9 months, not right away…. But you can almost — saying it out loud is so helpful. So I think probably as I   was sitting there* [therapist's office] *I realized yep, sounds like OCD, told her some of my history. She's like yeah, it is just heightened postpartum. So it wasn't like brand new…my OCD and anxiety has always kind of been there.*

She goes on to reflect,

> *But I can see how….scary that must be for someone who has never had any OCD symptoms, and then all of a sudden you are just experiencing….I mean, I can see how that would be so confusing and so debilitating* (Violet)

Seeking Answers, Seeking Support: The path to diagnosis

When initially interacting with health providers prior to diagnosis and treatment, mothers experienced difficulty describing their postpartum experiences with ppOCD, especially the content of their intrusive thoughts, either due to fear of stigma, (as discussed in the previous theme) or the inability to explain their experience in terms that others might understand. Notably, mothers also experienced that the standardized depression screening instrument administered at the office of their obstetrician or midwife did not capture their postpartum experience, nor was it helpful for facilitating a conversation with their provider.

> *Still, to this day, all of the bjillion questionnaires you have to fill out postpartum, they are still all related to depression* (Violet)

> *Well you see those screenings they give you…. 'do you cry often?' Yeah, I cry! But I'm not depressed.* (Lark)

There should really be more to that questionnaire. There should be a postpartum counselor that you go see, that first week, to have a discussion…I mean, how many women do you think lie on that form, probably thinking—if I admit this, they are gonna take my baby (Sofia)

While some mothers did receive referrals for psychiatric/psychological treatment from their providers after reporting emotional distress postpartum, either verbally or on a standardized screen, the referrals given were perceived to be non-specific, inappropriate, or inconvenient for their needs.

I talked to my Dr…I think at this point there was more information on just, you know, postpartum anxiety. They gave me a referral for a psychiatrist. I called, and there was a year-long waitlist for the psychiatrist they recommended. A. YEAR. LONG. (Violet)

I went to the OB…but I mean, they don't specialize in this kind of stuff, they gave me two referrals for psychiatrists, and I think they were just… names. Anyway, it was a month to get in. And I'm like a month? Oh my God, a month! I'm not going to make it through this…(Lark)

Discouraged with long wait times for mental health care, health providers and systems that felt dismissive, and feeling fearful as ever, mothers soon came to the conclusion that would need to engage in an independent search for support if they wanted to get the right help. Not sure where to look, internet research became the primary means by which mothers sought support and resources. Violet continues,

So, I just took it into my own hands. I went online and found a therapist in [suburb]. *I just found my own therapist before the psychiatrist they recommended because….yeah, a year!*

On the other hand, Amber was able to get an appointment rather quickly with the perinatal psychotherapist recommended by her Ob/Gyn practice. However, as described in the previous section, she felt she was "misunderstood" and "misdiagnosed" by this provider. When she returned to the health practice searching for a different provider, she was told that the therapist she had already seen was the only one they had, and no additional offers to facilitate help-seeking were made by that particular practice. Later, when Amber's untreated symptoms increased to the point of needing to present at urgent care, she was referred to a psychiatrist by

the urgent care doctor. This provider was perceived to be competent and helpful, albeit unable

to distinguish OCD.

> *When I met with the psychiatrist, I told him everything—he never really picked up on the fact that it was OCD, but he was wonderful with the medication aspect. He did what I felt comfortable with and never pushed me to take anything. I did Xanax and a sleeping medication, and it helped the panic attacks, and at least I could sleep again.*

While Amber still felt overwhelmed by her symptoms, she perceived that the medication helped

enough for her to attain a sense of relative stability so that she could focus on the difficult task of

finding the "right" mental health provider for more specialized support.

> *It's really hard to find a therapist when you've never done it before. I had no idea how to pick one, or what all the criteria meant. I just wanted help!*

She continues,

> *I came across information on postpartum OCD, specifically sexual OCD, while I was searching* [online] *for a new therapist. A lot of the symptoms resonated with me, and I printed out and highlighted the parts that applied to me. I then made an appointment with two therapists—a perinatal therapist, who specifically deals with postpartum moms, and one with a therapist who specializes in OCD….I started with ['OCD therapist'] in October, and I saw her until the end of April. She confirmed my OCD and we did some exposures and talked through some of the depression. I learned all I could about OCD and started to differentiate between what was an OCD thought and a regular thought. I faced my triggers, told my husband how he could stop enabling my need for reassurance, and just worked a ton on self-acceptance. I battled other forms of OCD—relational, losing control, and moral. All horrible, but manageable, once I realized they were OCD* (Amber)

For most mothers, the process of formal help-seeking was very self-driven. Peers and

family had a role, for sure, but that role was mostly in the background as a source of comfort

and support, and as aids in making major treatment decisions (e.g., decisions about whether or

not to seek emergency care). However, an exception to this general trend was found in the case

of Iris. Because Iris' obsessions were primarily physical/medical in nature, she was not entirely

convinced that her experiences of intense anxiety about the possibility of suspected illness (or

the potential consequences of confirmed illness) were unwarranted. Like the other participants,

Iris understood that something was wrong—she just thought there was a physiological

explanation. As such, she frequently presented to the ER seeking treatment or reassurance for

assorted physical complaints, called and made appointments with primary care doctors and her

children's pediatrician whenever she felt something was amiss. Her understanding of her illness

was further confounded by "real" medical incidents and emergencies (e.g., her newborn getting

the flu and a high fever at less than three weeks old; a young friend's unexpected death by

heart attack). Retrospectively, Iris was able to recognize that her symptoms were, in fact,

related to ppOCD, but not until several months after onset.

In the meantime, her family (husband and father) were instrumental in getting her to

recognize the severity of her symptoms. However, there was a sense that her father (a mental

health professional) and her husband, were "against" the methods of her long-time therapist,

who Iris respected and trusted. This dynamic created a stressful situation as Iris felt she was

being pulled in two different directions—her husband and father telling her that she was

severely mentally ill and needed more help, and her therapist, who encouraged Iris to keep

treating her anxiety as usual.

> *My husband was always saying, 'something is wrong with you.'*

> *I remember one time there was this stuff about AFM going on, this disease that paralyzes kids. And I had been doing all of this research about it. And one night my son was in his crib and he said, 'my legs hurt'.*

> *And I was like, 'Oh my God! You* [husband] *have to come here, I'm not doing this by myself!' And I'm having a panic attack…. I guess in retrospect, it was probably a compulsion, but I was like,*'[Son], *get up! I need you to do this! I need you to jump like this!' And of course he thinks it's funny because he's three and it's—in retrospect, if your legs hurt they probably aren't paralyzed because you can feel something.*

> *But my husband was like, YOU ARE CRAZY! And* [later] *my therapist was like, ok, its anxiety, you're worried….and my husband was like*, *your therapist does not realize how bad things are, and she does not realize how dysfunctional you are. She's not seeing you on ten, and it changes the ballgame when you are on ten.*

Iris goes on to speak how upon her father and husband's insistence, she began to call her
therapist during times "when I would get really upset at home".

> *I think that's when she* [therapist] *realized how bad things really were. She was like, ok, this is actual OCD, you cannot stop googling, this is a compulsion you can't control, and you're actually going to need to go to an intensive outpatient treatment program* (Iris)

After several weeks of attending an intensive outpatient program, Iris' and her therapist began a course of treatment that more specifically targeted OCD symptoms, as opposed to generalized anxiety, which Iris experienced as far more efficacious.

For mothers in the sample, the path to an accurate diagnosis was wrought with interpersonal and structural challenges. Mothers' initiative and persistence in their quest for answers as well as the support of their loved ones, facilitated obtaining the proper diagnosis and associated treatment resources.

Knowledge is Power: Demystifying ppOCD

After mothers had arrived at a diagnosis, they made efforts, both with their mental health providers and on their own, to educate themselves as thoroughly as possible about OCD—as a stand-alone mental health diagnosis as well as in the postpartum context. As mothers learned more about OCD broadly, as well as the nuances of their own OCD, they became more confident in their ability to manage it. Participants primarily utilized the internet to search for support, resources, and "answers". Mothers consulted books, articles, websites, and other print and virtual resources to in an attempt to acquire more knowledge about ppOCD. Mothers perceived that this practice allowed them to better recognize and address symptoms, as well as explain their experiences to their partners and families. This was evident throughout data collection; mothers demonstrated a sophisticated knowledge of OCD, as well as an introspective awareness of how OCD symptoms affected them uniquely, and how to respond to them.

> *I think it should be stressed, it's not the thought that's bothering you—but how hard is it to get that thought out of your head? Um, a kind of test have for myself of how bad I'm panicking* [obsessing] *is if I can read a page of a book. There are times I can't get through the page—I can't stop thinking about whatever the distressing thought is. And I think that's a better indicator of OCD than what the thought is. It's how hooked you are on it* (Gemma)

> *Knowledge is number one. Educating myself. Knowing that I'm not alone. That this how my synapses work. Just having the mindfulness—this book calls it an impartial spectator in your brain. And the impartial spectator is like a referee in your brain. So just labeling it—that is an intrusive thought. Does not mean it's true. So first of all, just having the*

mindfulness to flag the thought. So if I have a thought, that kinda stops me in my tracks, rather than believing its true I just kind of take a breath, take a pause—That's an intrusive thought. That does wonders (Violet; Book reference: *Brain Lock,* [Schwartz, 1996])

Several mothers discussed the helpfulness of social media, which allowed them to search for support while maintaining a degree of relatively anonymity, especially as they were actively battling the experience of shame and stigma/self-stigma in the context of their ppOCD. Social media platforms were viewed as useful for finding both practical information and a sense of connection and solidarity with people all over the world who were experiencing similar challenges.

When I was just desperate to see other people who understood, I'd look at tags, I'd look at hashtags. So I did like, #OCD, #Postpartum OCD, this woman came up. And she is a big advocate for it and I follow her [pause].

She continues,

I *know, that sounds so pathetic, to look at hashtags* [on Instagram]. *But when you are desperate….no one else understands. So….. Hashtag maternal OCD.* (Lark)

Blog and Vlog-type websites were especially helpful to participants feel they were not alone in their experience, particularly among mothers who experienced intrusive thoughts related to physical or sexual violence/harm.

I beat myself up about it. Because of the type of OCD it was [sexual OCD]. I think the only thing that helped me to accept it better is when I came across this one [woman] who had a blog about it. It was called 'Not your Momma's OCD'. And she posts about her experience with harm OCD, and sexual OCD—I could never do that. I mean, I'm pretty open, but I could never be THAT open, and the fact that she was…it was like, ah! Ok, I'm not the only one. (Amber)

Becoming more aware and educated on ppOCD resulted in increased confidence in vocalizing their experiences and articulating their needs with family and loved ones. As they gained knowledge about their illness, its influences, and its treatment, they were able to more efficiently self-advocate for their needs with their families and partners. Sofia, who lived with her parents during the postpartum period, reflects,

Nobody in my family ever understood. I was the first one with it [OCD], *I was the first to breastfeed.... So, trying to explain all this stuff* [about ppOCD] *to everybody…it's like, no,*

I'm not just going to be ok. I have to work at it. My hormones are really fucked up! Chemically, everything in my body, and I'm trying really hard to get through it. So you guys need to listen to me, when I wanna talk, I don't need you to tell me that it's gonna be ok. I was educating everyone, I was educating myself. (Sofia)

With the support of her OCD therapist, Gemma now feels comfortable providing her husband with concrete ways to support her based upon her growing understanding of OCD intrusive thoughts and compulsions, and the ways in which they are perpetuated.

[My husband] *can fall prey to me convincing him that something is really wrong—that it could be something else. So he's under strict orders* [laughter] *to not believe anything I say, when I'm feeling like this. This is OCD—I don't need to go to the ER, I don't need to do any compulsions, I just need to sit here and wait for it to pass. He's very understanding, very supportive. So we've kind of implemented some things he can do when I'm not feeling well* (Gemma)

Exploring OCD broadly and postpartum OCD specifically through a self-directed process of internet research, social networking, collaboration with trusted health providers, and partners and family, promulgated a deeper sense of understanding of themselves—as human beings, mothers, and mothers with OCD.

4. <u>Learning to live with OCD: Acceptance and Resilience</u>

My OCD comes back/ it's something that I have/ that can surface/ but it's not in the forefront/ anymore /and it's less scary/ moving forward (Found Poem, "Amber")

The experiential theme *Learning to Live with OCD: Acceptance and Resilience* highlights the way in which mothers came to accept their diagnosis and move away from "a place of fear". As horrible as enduring ppOCD had been, or in some cases, continued to be, mothers had not found it entirely without purpose. Terrifying as it was, "fighting" OCD had drawn out strength and grit they had not known they possessed. As they moved through the help-seeking process, mothers experienced a sense of raw emotional vulnerability in disclosing their symptoms and processing their experiences. Enduring ppOCD, and beginning to come through on the other side, had allowed them to tap into the full extent of their power as women and mothers. In so doing, they felt better equipped to manage the inevitable future challenges of a condition they now regarded as chronic.

Externalizing OCD

A key component of accepting ppOCD was learning to view it as existing outside of oneself. Participants experienced a tremendous sense of relief when they started to see a clear distinction between ppOCD and themselves—when it started to become apparent on both an emotional and cognitive level that their thoughts were the result of a treatable mental illness, and not evidence that they were deranged humans or unfit mothers. Amber reflects,

> *Looking back, I can tell what* [ppOCD] *was, but back then, I didn't know. I worked on surrounding myself with all the forms of education about OCD and that helped me to figure out that it wasn't….me. And just understanding what was an OCD thought, and what was a regular thought, and scary thoughts don't mean scary actions. That having that type of anxiety wasn't a reflection on my character, it was just something I happen to have (Amber)*

Mothers viewed their OCD as an adversary — one that they were trying to constantly trying to overcome. The "battle" against OCD was viewed as an internal battle against an external, powerful (and guileful) entity. "OCD" could over that could overpower their minds if they were not careful; if they did maintain a constant awareness of their cognitions. At the time of the interviews, some mothers felt they had all but defeated the OCD beast. Others felt they were still fighting, but making progress.

> *For me, medication is non-negotiable. And the sooner I kind of came to terms with that, the easier things got. I feel like things are getting easier. The little bump-ups, the flares. Like, even if I was in the middle of a flare and always felt as bad as I feel now, there have been worse times. Life is still worth living, I can still enjoy my life!* (Gemma)

> *The most potent thing—to like, kill OCD, is to admit the thought. Like, listen to what my OCD did today….* (Violet)

As mothers became increasingly engaged with the treatment process and acquired additional knowledge, they felt strengthened in their ability to combat OCD. In the following passage, Sofia recalls a particularly confrontational experience with her OCD:

> *I was terrified to be alone with her. Unless I like, went out. And did stuff. And I remember one time, I think it was June—we were at [nature preserve]. There is that downhill and then it goes a little bit, and then there is a little path to the water. And I stop, and I STARE at it. And it was like a movie, and I was like, "What if I.......?" And then I screamed at the top of my lungs, FUCK YOU! I'M DONE WITH THIS SHIT! And then I just walked. And I called* [therapist]. *[Laughter]. I'm like, I'm in the woods right now in*

[suburb], *and this is what happened, and she's like, Yes! You go, girl! All excited about it….*

[laughter]

….It felt so good that all the medicine I took, and the psychiatrists, the psychologists, the mom groups, the talking to other women, and reading positive stuff….. so, it was at that moment, it was kinda like, wow, I have control over this now, everything has kicked in (Sofia)

Moving away from a place of fear

Accepting OCD as a chronic illness was essential to mother's perception that they were coming loose from its chains—that they could regain a sense of joy and normalcy in their lives. While all participants described feeling substantially better at the time of the interviews than they did prior to treatment in their early postpartum days, most still experienced difficulties with OCD symptoms.

When I am feeling good, it's like, don't ask me if I'm anxious, don't bring it up right now! I just want to be normal. Because one of the things I think I struggle with is accepting that I have it and that its chronic, and it will probably come back at some point, and that is something that needs to be managed…But I do feel like it's getting easier (Gemma)

Again, it [OCD] *will probably always be there, but I mean, it's the noise is so turned down in my brain than it once was. Where it was like up at a very high level before, now it's just occasional white noise in the background.* (Violet)

As participants came to understand OCD more and more, they realized they would have to actively continue to manage the symptoms of their illness, through medication, therapy, self-care, and peer support, and continuing psychoeducation. Slowly, they came to learn to accept the chronicity of OCD, even as they moved out of the postpartum period, and returned to a sense of normalcy, at least for pockets of time.

Sometimes I've forgotten to take them [medication] *for not like five days, and that is when stuff will start happening. And that's when I'm like ugh, I'm not cured yet. And I know I'm not cured yet, because I keep having these stupid visions. And then there are times when I'll think of something completely irrational. What if we get in a car crash? And die? A flaming car crash….*

….But I don't not want to live our lives to the fullest because I'm afraid. I'm afraid of a lot of stupid things. More than anything, I'm afraid of death, to the point I've lost sleep. Um, and there are things I'm afraid of that I won't tell me daughter because I don't want her to be afraid because of me. I ain't doing that shit…(Sofia)

Iris also spoke of not wanting to produce fearfulness in her children, and discussed the importance of maintaining vigilance in her interactions with her children:

> *My biggest worry with my kids and how it* [OCD] *impacts my role as a mom, in a podcast they were talking about how OCD can be genetic. And I'm like Oh my God—what if he ends up with debilitating OCD, because you can see how it can happen so fast. So that's one thing, and the other thing with my kids is being really aware of not wanting to be a parent who raises kids who live from a place of fear. So…like, how do I make sure I am not projecting whatever might be wrong with me at that moment on them….?* (Iris)

Indeed, throughout the research process, it became evident that the well-being of mothers' children and families was the primary motivator for earnest and consistent engagement in their battles with OCD.

C. Conclusion

Mothers felt that their journey through ppOCD had transformed them on a deep level. As mothers reflected back on their experiences, they painfully recalled places and spaces of immense fear and shame. Motivated by a desire to feel connected and understood, and to unearth an experience of joy in mothering along with the struggles, mothers searched broadly for solutions and support. Their searches were fruitful in obtaining an OCD diagnosis—the first step on their subsequent journeys to understanding and acceptance.

V.   DISCUSSION

To date, there is no published literature on mothers lived experiences with ppOCD, including help-seeking for ppOCD, gathered from their own perspectives. The aim of this exploratory, qualitative, phenomenological study was to uncover an in-depth understanding of six mothers' lived experiences with ppOCD, with a focus on their help-seeking experiences through the exploration of two overarching, overlapping research questions: 1) What is it like to experience ppOCD? 2) What is it like to seek help for ppOCD? In line with phenomenological research methods, findings presented in chapter four and discussed here were derived from mothers' self-directed, unstructured accounts of their experience with ppOCD (van manen, 1997). While I did ask specific questions as they came up organically in the interviews and member-checking phone calls, mothers maintained primary control of the way in which they structured and ordered their narratives. In this sample, help-seeking experiences emerged as an inextricable component of the overall experience with ppOCD. In turn, the overall lived experience of ppOCD provides context for a deeper understanding of the help-seeking experience. Thus, I will discuss the research questions in an integrated manner, first summarizing participants' broad lived experience with ppOCD, and then delving more specifically into their help-seeking experiences.

This discussion section begins with an integrated summary of the study's research questions in relation to the findings discussed in Chapter four. As the literature on ppOCD, specifically, is scant, parallels and divergences with the help-seeking literature among two populations: 1) Women with perinatal mental illness, and 2) adults with OCD, are discussed throughout. Findings are then further considered in the context of the NEM and the illness career (Pescosolido, 1991; 1992). Next, implications for health care practice at the provider-

level and system-level are presented. The chapter closes with a discussion of the study's

limitations and suggestions for future research.

A. Integrated Summary: Research Questions

The lived experience of ppOCD was, profoundly disturbing. Mothers described a life-

altering experience, as they had expected would come with the birth of their new babies.

However, what they believed would primarily be a time of immense joy spotted with challenges,

turned into a time of great tribulation with few, if any, bright spots. In the words of one mother,

ppOCD was "the absolute worst thing I have ever had happen to me". Enduring ppOCD was as

humbling as it was disorienting — mothers who ordinarily viewed themselves as strong,

independent, and capable were rendered helpless, powerless. The onset of ppOCD intrusive

thoughts and images hit suddenly and powerfully, much like a tidal wave, in which mothers felt

entangled until they arrived at a diagnosis and were able to access appropriate help.

In accordance with cognitive models of OCD, which posit that OCD symptoms are

activated by misappraisals of naturally occurring intrusive thoughts (Salkovskis, 1985) mothers

in this sample seemed to have been ensnared by passing intrusive thoughts that occurred

during the earliest days postpartum, which could seem to appear at random, or sparked by

current events, or even the realization that with an infant, "there are dangerous things

everywhere" (Lark). Indeed, it is common for any new parent to experience random, occasional,

thoughts or images of harm coming upon a newborn (Fairbrother & Abramowtiz, 2007). The

difference for these mothers, however, was that the thoughts would not disappear or subside—

they were "etched in stone" (Violet) in mothers' minds. While the content of their ppOCD

intrusive thoughts was extremely upsetting—the more distressing element was the fact the

thoughts and images could not be escaped, as described by Gemma — "it's not the thought —

it's how hooked you are". Metacognitively, mothers wondered what the mere presence of such

disturbing thoughts *meant* about them. Were they "bad mothers"? Evil people? Insane?

Both mental and physical stressors seemed to exacerbate OCD symptoms in postpartum mothers. Hormonal changes, in particular, were associated with the emergence or worsening of symptoms. This is consistent with Guigliemei's retrospective study (2014), which found that female reproductive cycle events were associated with the exacerbation or onset of OCD symptoms. In this dissertation study, multiple mothers experienced a marked exacerbation of their OCD intrusive thoughts and associated compulsions and anxiety during times of hormonal fluctuation over the postpartum period (e.g., weaning from breastfeeding, introduction of IVF hormones). For two mothers, these changes culminated in suicidal ideation and subsequent presentation to emergency/urgent care services.

In this sample, participants spoke of experiencing structural barriers inside health systems in the form of poor continuity of care and follow-up, unclear guidance about how to access referrals, as well as long wait times to see mental health providers (Carillo et al., 2011). This finding is consistent with the findings of previous studies among women with postpartum depression or un-specified postpartum emotional distress, which have found that a lack of guidance on how to follow-up with mental health referrals leads to reduced help-seeking (Dennis & Chung-Lee, 2006; Henshaw et al., 2013; Millett et al., 2017). However, in this sample, mothers were able to navigate these system-level structural barriers with relative ease, as they quickly decided to engage in an independent search for resources outside of the referring health system. This was made possible, in large part, by access to financial resources, as well as the perception of emotional and practical support from spouses and family. For example, in some cases, to access specialized mental health care sooner, mothers needed to make appointments with providers outside of their insurance network and accrued the associated out-of-pocket costs for services. As these interviews took place prior to the onset of the COVID-19 pandemic, mothers had been receiving formal health services in-person, with sporadic, occasional phone contact as needed. Notably, no mother mentioned experiencing financial barriers, such as lack of health insurance or under-insurance, or structural barriers external to the health system such

as inability to access childcare or transportation (Carillo et al., 2011). In this regard, mothers recognized their relative privilege and the impact it had on their access to health care. For example, Amber stated, "I particularly feel like I have a lot of support. I think that I have a lot more resources and support than most people who would have gone through what I went through….. And that helped a lot."

In addition to tangible resources, mothers also acknowledged the presence of strong social support in their lives. Mothers perceived their partners as supportive and non-judgmental. Other key supports included mothers' parents, sisters, and sometimes, close friends. These members were not actively involved with health decision-making or treatment, but served to provide a supportive presence, and occasionally, advice.

With regard to formal help-seeking, knowledge barriers, which may be conceptualized as a subcategory of cognitive barriers (Carillo et al., 2011), were more prevalent than overt structural or financial barriers to care. For example, participants initially lacked knowledge about how to distinguish postpartum mental illness, broadly, from "normal" postpartum emotional distress. This finding is consistent with findings from previous qualitative and quantitative research examining help-seeking barriers among mothers with symptoms of perinatal depression (Byatt et al., 2013; Megnin-Viggars et al; O'Mahen & Flynn, 2008). With regard to OCD, specifically, limited knowledge and/or misunderstandings about OCD-associated obsessions and compulsions limit the ability for one to self-identify symptoms as a treatable illness and have been cited as major barriers to accessing mental health care for individuals suffering with OCD (Olson et al, 2007; Robinson et al., 2017).

When they did eventually make the decision to seek help, mothers were unsure about who to contact or where to initially present, representing another form of knowledge barrier (Carillo et al., 2011). In the earlier days of their illness, participants experienced severe psychological distress in the form of anxiety, panic, and an oppressive sense of fear. At the height of their ppOCD symptoms, several mothers also spoke of feeling unable to eat, drink,

and sleep. Physical complaints, such as headaches and gastrointestinal issues were a common occurrence. Fatigue and a sense of physical exhaustion, juxtaposed against an overactive, hypervigilant mind. Commonly, postpartum mothers initially present to their birthing professionals (midwives, ob-gyns) with both physical and mental health complaints in the weeks and months following birth (Khan, 2015). The mothers in this dissertation study were no exception—they ultimately initially contacted or visited their perinatal/birth providers to seek help.

However, across participants, perinatal and primary care providers were not viewed as prepared and/or qualified to adequately assess (or differentiate) mental health problems. Unable to arrive at a definitive diagnosis, participants were offered prescriptions for sleeping medications or anti-depressants, which were perceived to provide some limited relief but not to address the root of their symptoms or alleviate their intrusive thoughts. Other mothers were given referrals to psychiatrists or psychotherapists. However, providers didn't directly connect mothers with these referrals, and when they called to schedule they learned they would need to wait several weeks, months, or for one mother, a year—to get in. While mothers in this sample were able to find other resources for help independently (i.e., without health provider/ health-system assistance), they were struck by the perceived lack of assistance and concern by their perinatal health providers. Notably, this was viewed as more of a limitation in the health system (e.g. perinatal/postpartum appointment structure) rather than the individual provider. Speaking to this fact, during her follow-up phone call, Lark observes:

> They (the Obstetrician) are your go-to, for everything, the whole pregnancy, the whole nine months. You see them all the time. Then, you have the baby….and it's like, well, good luck! They have the plan set up for the baby….but where is the plan for the mom?

Knowledge barriers about the nature and origin of the emerging illness as where to present for help did not necessarily prolong mothers' actions to actively seek help, but they did make the help-seeking process more confusing and less efficient.

B. <u>**The Network Episode Model**</u>

This section explores the findings through the lens of the NEM (Pescosolido, 1991), with attention to the non-sequential stages of the illness career and the impact of social interactions within each stage. If we consider the fluid, multi-stage process of the illness career (Pescosolido, 1991; 1992), or an individual's trajectory through the health system, we can appreciate a more nuanced understanding of the way in which system-level structural barriers and knowledge barriers combine with interpersonal relationships and the social dynamics of help-seeking. A basic premise of the NEM is the notion that individuals facing a mental health crisis will activate their social networks for consultation when their own coping abilities are overwhelmed (Pescosolido 1991, 1992). In turn, both lay and professional network members significantly influence the help-seeking process throughout an episode of mental illness (Pescosolido, 1991, 1992; Pescosolido et al., 1998). The key assumption of the NEM is that "lay and professional networks play a central role in influencing response to illness" (Berry et al., 2016). Presumably, supportive responses from network members increase help-seeking behaviors, and stigmatizing, judgmental, or indifferent reactions will minimize help-seeking behaviors (Pescosolido, 1991;1992; Pescosolido et al., 1998).

When mothers were in the early stage of recognizing their illness as a mental illness, the initial decision point involved when, with whom, and to what extent to share their early internal experiences with ppOCD. In this sample, mothers first disclosed they were feeling mentally unwell to their partners (3 mothers), their parent (2 mothers), or their sibling (1 mother). After having the initial conversation(s) about their mental health, mothers expressed great relief when they perceived their partners families as supportive and understanding. However, mothers avoided disclosing the specific *content* of their intrusive thoughts, even when partners and family were perceived as supportive. This was largely thought to be due to embarrassment, shame, and/or difficulty articulating their experiences in a manner in which they thought would be "understood". In general, partners and family were perceived to encourage formal help-

seeking—although they differed in the ways they went about doing so. Unsure about how to provide support without fully understanding what was happening, some partners and family occasionally became frustrated with mothers, resulting in verbal conflicts about how, where, and when to present for treatment. Retrospectively, mothers tended to view conflict and confrontation from their partners and loved ones as a form of encouragement to seek additional help. While informal health advisors (Berry et al., 2016) provided suggestions and opinions about providers and level of care needed, mothers perceived that it was they, themselves, who had the final say with regard to their formal help-seeking decisions.

Participants felt more comfortable divulging their symptoms and discussing their ppOCD experiences with specialist mental health providers (psychiatrists and psychotherapists) than to family/peers or health providers who were not mental health specialists (primary care doctor, ER physician, etc.). Some mothers developed trusting relationships with their mental health providers almost immediately, while some took multiple sessions over the course of several weeks or months. Some participants never developed this type of relationship, and eventually found another provider who was perceived to provide support more aligned with their needs. The process of symptom disclosure was ongoing — mothers tended to disclose symptoms "little by little", providing more detail about the content of their intrusive thoughts, the perceived intensity of their compulsions, and/or their associated experiences with anxiety and panic as they built trust with their providers. Most importantly, mothers first needed to believe that their mental health provider would not "report" them for the content of their intrusive thoughts, and/or "take away my child". This was especially true if participants had received stigmatizing or ambiguous responses from a provider they had seen previously.

Obtaining an OCD diagnosis, from a supportive health provider, was seen as a positive "turning point" in the course of the illness career for all of the study participants. Once mothers knew that their experiences were related to OCD, they felt a burden lifted. Mothers gained confidence in their decision-making about their health and health care, and the process of help-

seeking took the form of seeking out additional knowledge about ppOCD specifically, as well as OCD broadly—via books, social media, blogs/vlogs and podcasts in order to supplement their work in therapy and/or prescribed medication.

In this sample, increased knowledge about their mental illness, in combination with health provider support, resulted in increased confidence in mothers' ability to talk about their symptoms, involve their partners and other informal supports in their treatment, as well as increased self-advocacy in talking about their mental health-related needs with both partners/family and providers. As they evolved in their help-seeking process, participants disclosed the content of their intrusive thoughts, as well as the extent of any existing behavioral compulsions, upon a trusted mental health provider's advice. Involving partners and (to a more limited extent) parents with the treatment process (e.g., inviting them to therapy sessions, providing psychoeducation materials) promoted greater understanding of OCD its underlying mechanisms. In sum, the support of providers and partners, as well as the independent pursuit for increased knowledge about ppOCD, and how to counter it, were key in being able to accept the presence of OCD in their lives and move towards relative health and stability.

C. Implications for Health Care

1. Health System Implications

Screening and Provider Training. Given the potential severity of ppOCD and its estimated prevalence, screening for ppOCD in health practices serving perinatal women is indicated. In the United States (and many other countries) peripartum depression screenings are routinely administered to perinatal women during pregnancy, immediately after birthing, as well as during the compulsory postpartum appointment with the birth provider (usually occurring 2 or 6 weeks postpartum, depending on delivery method). While screening for depression in peripartum women remains essential, they have not been designed to identify co-occurring mental illness, such as OCD. As provider resources for identifying and treating ppOCD are

extremely limited (or nonexistent), the creation of a health provider toolkit, for the purposes of screening/assessment, referral, and treatment services is indicated. Health providers who have regular contact with perinatal women in obstetric, pediatric, and primary care settings should receive training in the identification of potential maternal mental illness and referral procedures. Health providers serving perinatal women should understand that a negative depression screen does not necessarily mean a woman is not experiencing postpartum mental illness and further intervention is not warranted. Women's health providers should be aware that there is evidence to suggest that ppOCD may emerge not only immediately after birth but may accompany hormonal changes — such as those caused by IVF, weaning from breastfeeding, or menstrual cycle events.

Pregnancy/Childbirth Classes and Support Groups. Most women in the study had attended at least one health-system sponsored pregnancy health and birthing preparation class. Mothers felt that while the classes were beneficial for preparing for labor and delivery, they provided little information on common and potential challenges during the postpartum period— including the onset of maternal mental illness. In this sample, all mothers expressed that would have liked to receive information and education on common physiological and mental health challenges that may emerge after birth. As partners (or other social supports) often attend prenatal/childbirth classes, prenatal classes represent an opportunity to provide basic information on possible maternal mental health conditions, such as ppOCD.

In addition to prenatal classes, most mothers attended a health-system sponsored support group for new mothers. However, these support groups were perceived to be tailored to mothers experiencing "normal" postpartum difficulties, or for mothers experiencing PPD specifically. Mothers tended to find these types of support groups as unhelpful, and in some cases, they were experienced as perpetuating self-stigma, as mothers compared their own experiences and thought content with that which was expressed by other mothers. Before the recommendation to attend a general, or PPD-specific support group, is given, mothers should

be screened and assessed by a qualified mental health provider to see if such support groups would be appropriate for their needs and goals. Health system websites advertising perinatal/postpartum support groups should provide detailed information about the group, as well as its scope and limitations.

2. **Implications for Direct Health Providers**

Obstetricians/Gynecologists, Midwives, Supportive Birth Professionals. Ob/gyns and midwives are among the first health professionals mothers contact when they began to experience signs of postpartum mental illness (Khan, 2015; Byatt et al., 2013). Women's health providers and birth/postpartum specialists (e.g., lactation consultants) are in the unique position to be able identify potential ppOCD (and other mental health problems) among mothers early, and provide expedited referral and linkage. While participants saw multiple physical and mental health providers along their help-seeking journey, the first provider they thought to contact when their symptoms emerged was their obstetrician or midwife. Unfortunately, in this sample, these health professionals were perceived as having little to no clinical awareness or knowledge of ppOCD and its manifestations. Birth and postpartum health professionals working in health care should have at least a basic general understanding of ppOCD and other common maternal mental illnesses and the ways in which they may present. Further, providers should promptly link women experiencing perinatal emotional distress with a social worker who can provide comprehensive screening, assessment, and referral services.

Clinical Social Workers embedded in health systems. Both mothers who presented for urgent care interacted with clinical social workers during these visits. LCSWs working in emergency care/urgent care (or in perinatal care) within a larger health system should have advanced knowledge and training on ppOCD. Importantly, social workers' settings should have a clear understanding of the difference between the presentation of ppOCD from the presentation of postpartum psychosis (PPP). Treatment for PPP commonly requires immediate

hospitalization for safety and stabilization, while this is usually not required for ppOCD (PSI, 2021). However, while not experiencing a psychotic illness, mothers presenting with ppOCD are in great psychological distress. Notably, three of the six mothers in this sample disclosed having thoughts of suicide prior to receiving treatment for their ppOCD. Notably, mothers expressed that they viewed wait times for health system-provided referrals unacceptable—that they could not wait a month or more to be seen by a mental health provider. Whenever possible, social workers should provide case management and directly link individuals with services. In cases where long wait times are unavoidable, bridge services should be offered.

Outpatient mental health providers (LCSWs, psychologists, licensed counselors). Outpatient mental health providers who work with perinatal women should be prepared to assess and treat (or refer out) those who present with OCD-like symptoms during the first year postpartum. Exposure with Response Prevention (ERP) is viewed as the gold-standard of Cognitive-Behavioral treatment interventions for OCD that includes behavioral compulsions, including sexual and harm/OCD (Young et al., 2021). Mental health providers who work with perinatal women should be familiar with OCD and its possible presentations during the perinatal period. Providers who intend to provide treatment for ppOCD should receive training in ERP, its uses, as well as individual-level contraindications. As pharmacotherapy is often (but not always) indicated to assist in the management of ppOCD, mental health providers should provide referrals and linkage to prescribing medical professionals and/or engage in consultation as indicated.

Mindful awareness of the therapeutic process of engagement/rapport building may be especially important with women experiencing ppOCD. For the mothers in this study, a perception of provider warmth, empathy, and acceptance promoted more complete symptom disclosure, and helped to establish the foundation for a strong therapeutic relationship. Additionally, mother's appreciated when providers communicated knowledgably about OCD, and framed ppOCD as treatable mental disorder. For mothers who experienced intrusive

thoughts of directly harming their children, psychoeducation and "normalization" of their symptoms was viewed as extremely helpful in reducing self-stigma.

Finally, mental health providers should maintain an awareness that mothers presenting with ppOCD may not disclose all of their symptoms, or the full extent of their symptoms, all at once, complicating the process of diagnosis. When working with postpartum women, providers should be aware that the fear of children being removed or taken away may exist, and that it may persist throughout the treatment process, even if it appears a trusting relationship has been established. Providers should be communicate early, explicitly, and as needed about confidentiality and its limits. During these communications, any expressed myths or misconceptions about criteria for both voluntary and/or involuntary hospitalization should be discussed honestly and transparently, and any questions about these processes should be discussed to the client's satisfaction.

3. **Implications for Health Science Education**

Finally, this research has important implications for Education in the health science fields, especially within the clinical curricula of health professionals such as social workers, nursing professionals, specialized medical practitioners, psychologists, and mental health counselors. Research suggests that approximately five percent of women may be affected by OCD symptoms during the perinatal period (Miller et al., 2013). However, among the mothers in this dissertation study, health providers who did not specialize in the treatment of OCD were perceived to be generally uneducated about the clinical presentation, assessment, and treatment of perinatal OCD.

At minimum, the perinatal period, and the associated physical and socioemotional challenges women can encounter throughout, should be highlighted in both in-class learning and clinical practicum training. Health providers of all disciplines who work with perinatal women should be equipped with at least a cursory knowledge of the various forms of maternal mental

illness they may encounter, including ppOCD. Future health care providers should also receive

training in barriers and facilitators to health system access, diagnosis, and engagement with

mental health services among perinatal women. As accurate diagnosis is essential for planning

effective treatment, prospective mental health providers (e.g., LCSWS, psychologists) should be

receive thorough training in the clinical presentation of *specific* mental illness (e.g., ppOCD,

PPD, PPP) that has been known to emerge during the perinatal period.

D. Study Limitations and Directions for Future Research and Practice

This study has some limitations that need to be addressed. One key limitation involves

the lack of diversity in the sample. The sample consisted solely of mothers who self-identified as

white, female, cisgender, heterosexual, married/engaged and financially stable and/or

comfortable. The demographic constitution of the sample was likely affected by the study's

eligibility criteria and recruitment methods. Specifically, by requiring that mothers had an

established clinical diagnosis of OCD, I was only able to recruit mothers who had opportunity to

persist in their help-seeking efforts to the point of obtaining said diagnosis. Considering that all

mothers in this sample saw more than one health provider before arriving at an OCD diagnosis,

the perspectives of mothers with less access to the health system are notably absent. It is

important to note this omission, as women with less access to health systems are often lower-

income women of color—who also may be more likely to experience significant perinatal mental

illness in comparison with their white, financially-secure counterparts (Bryant et al., 2006).

Among this sample, cognitive barriers—such as knowledge barriers and self-stigma, were the

most common obstacles encountered when seeking and receiving help, with structural and

financial barriers nonexistent, or breakable. It's very possible that structural and financial

barriers to treatment might have been reported and with some frequency had individuals from

marginalized populations been included in the sample.

While the research questions and data collection methods (i.e., unstructured interviews) are congruent with qualitative phenomenological research methods (van Manen, 1997), the unstructured nature of the interview process necessarily leads to an uneven emphasis on some elements of experience versus others, with the specific emphasis varying by participant. This exploratory study's research questions and method of interviewing were intentionally formulated to capture the experience of ppOCD with regard to the elements that *emerged as most salient for mothers*, in an effort to learn more about the lived experience of ppOCD. However, as the knowledge base on ppOCD accumulates, other methods of data collection (e.g., semi-structured interviews, focus groups) may lead to a more specific understanding of particular elements of experience that affect help-seeking among mothers with ppOCD.

Future research efforts should focus on screening and identification of ppOCD with perinatal women. Research on the clinical presentation of ppOCD among mothers from varied socio-economic, geographic, and racial/ethnic background is especially indicated, as these women tend to experience even greater barriers to health care access, including structural barriers not experienced by the sample of the present study (Byatt et al., 2013; Carillo et al., 2011). Study designs that involve screening for ppOCD within health care settings among a perinatal population may allow for larger and more diverse samples. Specifically, help-seeking experiences of women with ppOCD within resource-poor communities, both rural and urban, and with communities of color are needed. Additionally

E. **Conclusion**

This study employed a qualitative, interpretive phenomenological research approach to gain an in-depth understanding of mothers' lived experiences with ppOCD, with special attention to their experiences of help-seeking through the lens of the Network Episode Model. While mothers in this sample experienced few structural barriers to healthcare access, they did experience internal (cognitive) barriers in the form of knowledge barriers. Knowledge barriers

were experienced as difficulty discerning their experiences as a treatable mental health condition, confusion about where to present for formal help-seeking, and lack of knowledge about the criteria/process of child removal for safety purposes. Mothers were eager to engage with the help-seeking process. However, perceived stigma from providers, as well as self-stigma often prevented full symptom disclosure, making the process of obtaining a diagnosis and appropriate treatment more difficult and convoluted. The support and compassionate guidance of knowledgeable mental health providers was seen as an essential ingredient in finding symptom relief, while emotionally supportive partners and families provided encouragement throughout the process of seeking and receiving formal treatment for their ppOCD.

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APPENDICES

APPENDIX A

RECRUITMENT FLIER

A RESEARCH STUDY ABOUT

POSTPARTUM OCD

RESEARCHERS AT THE UNIVERSITY OF ILLINOIS AT CHICAGO WANT TO LEARN MORE ABOUT WOMEN'S EXPERIENCES WITH POSTPARTUM OCD.

THIS STUDY MAY BE A GOOD FIT IF YOU:

- ☐ ARE OVER 18 YEARS OF AGE
- ☐ HAVE BEEN DIAGNOSED WITH OBSESSIVE COMPULSIVE DISORDER (OCD)
- ☐ EXPERIENCED NEW OR WORSENING SYMPTOMS OF OCD DURING THE POSTPARTUM PERIOD

THE STUDY INVOLVES PARTICIPATING IN ONE INTERVIEW AND ONE FOLLOW-UP PHONE CALL WITH THE RESEARCHER. THESE RESEARCH ACTIVITIES WILL TAKE APPROXIMATELY 90 MINUTES IN TOTAL. IN APPRECIATION OF YOUR TIME, YOU WILL RECEIVE A GIFT CARD FOR YOUR PARTICIPATION.

FOR MORE INFORMATION PLEASE CONTACT:

AMANDA KNEPPER, MSW, LCSW

PHONE: 630-649-9419

EMAIL: ALABAS2@UIC.EDU

Postpartum OCD V2 1-18-19

APPENDIX B

PRE-INTERVIEW PHONE SCREENING

Help-Seeking among Mothers with Postpartum OCD: A Phenomenological Exploration

Principal Investigator: Amanda Knepper, MSW

Faculty Sponsor: Chang-ming Hsieh, PhD

Help-Seeking among Women with Postpartum OCD: A Phenomenological

Exploration

Name of Participant: _____

Phone number: _____

Email Address: _____

1) Are you at least 18 years of age?

2) Have you had at least one biological child?

3) Have you been diagnosed with Obsessive Compulsive Disorder by a health
 professional? (Medical Doctor, Psychologist, Clinical Social Worker, etc.)

Approximate date of diagnosis _____

4) During pregnancy or after delivery, did your OCD symptoms:
        -Begin? (Initial onset)
        -Get worse? (Existing symptoms perceived to worsen)

APPENDIX C

INFORMED CONSENT

INFORMED CONSENT FORM
University of Illinois at Chicago
Research Information and Consent for Participation in Social, Behavioral, or Educational
Research

Help-Seeking Among Women with PPOCD: A Phenomenological Exploration

Principal Investigator/Researcher Name and Title: Amanda Knepper, MSW, LCSW
Faculty Advisor Name and Title: Chang-ming Hsieh, PhD
Department and Institution: Jane Addams College of Social Work, University of
Illinois at Chicago
<u>**Address and Contact Information:**</u>
Jane Addams College of Social Work, 1040 W. Harrison Street, Chicago, IL 60607
email: alabas2@uic.edu
About this research study
You are being asked to participate in a research study. Research studies answer
important questions that might help change or improve the way we do things in the
future.

Taking part in this study is voluntary
Your participation in this research study is voluntary. You may choose to say "no" to this
research or may choose to stop participating in the research at any time. Deciding not to
participate, or deciding to stop participating later, will not result in the loss of any services,
class standing, and/or professional status to which you are entitled, and will not affect your
relationship with the University of Illinois at Chicago (UIC) and/or University of Illinois
Hospital and Health Sciences System (UI Health), or any of the agencies or organizations
collaborating in this research.

This consent form will give you information about the research study to help you decide
whether you want to participate. Please read this form and ask any questions you have before
agreeing to be in the study.

You are being asked to participate in this research study because you have self-identified as
having experience with postpartum OCD.
10 participants will be enrolled in this research study.

This information gives you an overview of the research. More information about these
topics may be found in the pages that follow.

APPENDIX C (continued)

WHY IS THIS STUDY BEING DONE?	We want to find out more about women's experiences with Obsessive Compulsive Disorder (OCD) during the postpartum period.
WHAT WILL I BE ASKED TO DO DURING THE STUDY?	You will be asked to participate in a face-to-face interview about your experiences with Postpartum OCD. The interview will take place at a mutually agreed upon date and time. The interview is expected to last approximately 60 minutes. The interview will be recorded. The recording will be transcribed and used in the research process. The transcription will be deleted once all the analyses are complete. All identifying information will be removed from your interview transcript. Several weeks after the interview, I will send you an email with a written summary of the findings from your interview. You may also choose to receive a hard copy of the summary via USPS mail instead of an electronic copy. At this time, I will also send you a de-identified interview transcript, if you would like to have one. We will schedule a follow-up phone call. I will contact you by telephone at the scheduled time to discuss the findings and hear your feedback. This part is estimated to take an additional 30 minutes.
HOW MUCH TIME WILL I SPEND ON THE STUDY?	The interview will last approximately 60 minutes, and the follow-up phone call is estimated to last 30 minutes, for a total of approximately 90 minutes.
ARE THERE ANY BENEFITS TO TAKING PART IN THE STUDY?	Being in this research study may not benefit you directly. We hope that your participation in the study may benefit other people in the future by helping us learn more about Postpartum OCD.
WHAT ARE THE MAIN RISKS OF THE STUDY?	The primary risks presented by this research study are breaches of privacy (others outside of the study may find out you are a subject) and/or confidentiality (others outside of the study may find out what you did, said, or information that was collected about you during the study). To the best of our knowledge, the things you will be doing have no more risk of harm than you would have in your everyday life.
DO I HAVE OTHER OPTIONS BESIDES TAKING PART IN THE STUDY?	You have the option to not participate in this study. You may withdraw your consent to participate at any point without consequence.

APPENDIX C (continued)

QUESTIONS ABOUT THE STUDY?	For questions, concerns, or complaints about the study, please contact the researcher, Amanda Knepper, at (630) 649-9419, or email at alabas2@uic.edu. You may also contact the faculty sponsor, Chang-ming Hsieh (312) 996-0041, or email at chsieh@uic.edu.
	If you have questions about your rights as a study participant; including questions, concerns, complaints, or if you feel you have not been treated according to the description in this form; or to offer input you may call the UIC Office for the Protection of Research Subjects (OPRS) at 312-996-1711 or 1-866-789-6215 (toll-free) or e-mail OPRS at uicirb@uic.edu.

Please review the rest of this document for details about these topics and additional things you should know before making a decision about whether to participate in this research. Please also feel free to ask the researchers questions at any time.

During this study, Amanda Knepper will collect information about you for the purposes of this research. The information collected will include your name, your telephone number, your email address, and your mailing address. This information will be collected so that the researcher may identify you as a participant and contact you during the follow-up portion of the study. The researcher will screen for eligibility by asking if you are over the age of 18, if you have received a diagnosis of OCD, approximately when that diagnosis was received, and if you have at least one biological child. This information is collected to make sure that you are eligible for participation. During the interview, your responses to the interview questions will be audio- recorded. During the follow-up phone call, the researcher will take notes on the conversation. All information collected during the interview and follow-up phone call will be used for research purposes.

What will happen with my information used in this study?
Your identifying information (name, contact information) and eligibility information collected during screening will be deleted after all follow-up phone calls are complete and all data has been analyzed and written-up. However, you may request for the researcher to keep some of your contact information after this point if you would like to find out about results that may be published after the completion of the study. Your responses to the interview questions will be deleted from the audio-recording device immediately after the recording is uploaded to the computer that will be used for data analysis. The recording as well as your interview transcript will be deleted after all data has been analyzed and the results have been written up.

Will I receive any results from this study?

APPENDIX C (continued)

Yes. The researcher will send you a written summary of your individual interview interpretation by email or USPS mail prior to the follow-up phone call. You also have the option to receive a typed transcript of your recorded interview at this time.

If you would like, you may request to receive information about any publications (e.g. research articles) that are written about the study. **Please note:** This option would involve the researcher keeping some your contact information for a longer period of time (i.e. until published materials are available). If you change your mind about receiving published materials, you may contact the researcher at any time after the study is completed and I will delete your contact information.

What are the potential discomforts of the study?
The interview may involve questions of a sensitive nature about your experiences with postpartum OCD. If participating in the interview is emotionally upsetting in any way, you may choose to take a break for as long as needed; skip any questions you do not wish to answer; or withdraw your consent to participate at any point and end the interview.

What about privacy and confidentiality?
Efforts will be made to keep your personal information confidential; however, we cannot guarantee absolute confidentiality. In general, information about you, or provided by you, during the research study, will not be disclosed to others without your written permission. However, laws and state university rules might require us to tell certain people about you. For example, study information which identifies you and the consent form signed by you may be looked at and/or copied for quality assurance and data analysis by:

- Representatives of the university committee and office that reviews and approves research studies, the Institutional Review Board (IRB) and Office for the Protection of Research Subjects.
- Other representatives of the State and University responsible for ethical, regulatory, or financial oversight of research.
- Government Regulatory Agencies, such as the Office for Human Research Protections (OHRP).

For participants who viewed the recruitment flyer on Facebook: Please note that while Facebook will NOT have access to the specific data collected during this research, social media and internet sites may collect information regarding your online activities, as per the usage agreement you accepted to use Facebook, and will share this information with others, including advertisers.

A possible risk of the study is that your participation in the study or information about you might become known to individuals outside the study. Your personal information and interview data will be securely stored on a password-protected computer and/or in a locked file cabinet to prevent access by unauthorized personnel.

APPENDIX C (continued)

Your individual interview data will be stripped of all direct identifiers. Your identifying information will be stored in a password protected computer file that only the research team will have access to. You will be assigned a numeric code that links your identity to your interview transcript. The audio recordings collected during the interview will immediately be uploaded and stored on a password-protected computer. Audio recordings will be deleted from the recording device immediately after upload to the computer. Audio recordings will be deleted from the computer at the end of the analysis process. Electronic field notes and typed interview transcripts will be coded with your study identification number. Your name will not appear on these materials. Field notes and interview transcripts will not be shared with anyone outside of the research team. Field notes and interview transcripts will be stored on the researcher's password- protected desktop computer. I will provide you with a copy of your coded interview transcript if you would like to have one. Any handwritten notes related to your interview or the follow-up phone call will be coded with your identification number and stored in a locked file cabinet in the researcher's personal office. The master key linking your identifying information with your data will be deleted after the data is analyzed and results have been written up. If you request that the researcher keeps any of your contact information to contact you about publications of the study's findings after the study is completed, your contact information will be deleted after you are contacted with the publication information. You may also contact the researcher at any point if you change your mind about wanting information about publications, and your contact information will be deleted immediately.

When the results of the study are published or discussed in conferences, no one will know that you were in the study.

Please remember that there is an exception to protecting subject privacy and confidentiality if child, elder, and/or disabled adult abuse or neglect of an identifiable individual, or the threat of imminent self-harm or harm to others is disclosed. If such information is disclosed, the researchers may be obligated to inform the appropriate authorities.

<u>What are the costs for participating in this research?</u>
There are no costs to you for participating in this research.

<u>Will I be reimbursed for any of my expenses or paid for my participation in this research?</u>
You will receive a $35.00 gift card to your choice of either Amazon or a grocery store of your choice. You may let the researcher know your preference upon scheduling the interview. You will receive the gift card at the interview meeting.

<u>Can I withdraw or be removed from the study?</u>
If you decide to participate, you have the right to withdraw your consent and leave the study at any time without penalty.

APPENDIX C (continued)

The researchers also have the right to stop your participation in this study without your consent if:
- They believe it is in your best interests;
- You were to object to any future changes that may be made in the study plan.

If you choose to no longer be in the study and you do not want any of your future information to be used, you must inform the researcher (Amanda Knepper) or faculty sponsor (Chang-ming Hsieh). The researcher may still use your information that was collected prior to your written notice.

Remember:

Your participation in this research is voluntary. Your decision whether or not to participate will not affect your current or future relations with the University. If you decide to participate, you are free to withdraw at any time without affecting that relationship.

I have read the above information. I have been given an opportunity to contact the researchers and ask questions, and my questions have been answered to my satisfaction. I agree to participate in this research.

Signature of Participant:

_____ _____
Signature. Date

_____
Printed Name

Signature of Person Obtaining Consent: _____
Date

_____
Signature

_____
Printed Name

APPENDIX D

SEMI-STRUCTURED INTERVIEW GUIDE

General Experience, Experience with seeking/receiving treatment and social support

1) Can you tell me about experiences with postpartum OCD up to this point?
   Probe: Difference in sx; timing of worsening or onset

2) How has postpartum OCD affected your life? How has it affected your various life roles?
   Probe: Any interference; Mother, partner, career, etc.

3) Who have you told about your experiences? How did you decide who to tell?
   Probe: Reactions/perceptions of support; disclosure to health professionals; disclosure to informal supports

4) Did you participate in any type of formal mental health treatment (psychological and/or psychiatric treatment) specifically for OCD during the postpartum period? Why or why not?
   Probe: New OCD dx or existing; previous experience with bx health treatment

5) Did you utilize any other (non-professional) forms of support to help with postpartum OCD?
   Probe: Peer support groups; Internet resources, etc.

6) Overall, how do you feel about your experience with seeking help for postpartum OCD? Experiences receiving help?
   Probe: Ease of access; Barriers and facilitators; suggestions for improvement

7) Is there anything else you would like to say about your experience with ppOCD?

APPENDIX E

FOUND POEM EXAMPLES
(with modified formatting)

"IRIS"

This not normal/ it was crazy, crazy/ I'm maybe beyond/ a little anxious right now/ Something is wrong with me/ of course/ I feel terrible/ and I'm a little crazy/ but no said OCD/ What am I supposed to do?

I'm pretty high-functioning/ you know/ I get stuff done but/ panic attacks/ paranoid/ I can't do this/ I need an MRI/ Back to the Emergency Room/ knot in my throat/ paralyzed/ I'm going to die/ too anxious to eat/ my new thing is hives/ anaphylactic shock/ probably cancer/ can the stomach flu kill you?/ I'm going to die/

Then I'm fine/ I'm fine you guys/ I'm fine/ but in retrospect/ you're worried/ you are crazy/ and I can see him looking at me/ he is so fed up with me/ "This isn't real"/ No, this very real/ This is OCD/ This is my life/ This is actual OCD/ You know it can flare after pregnancy?/ No, I didn't/ No one told me

Knowledge is power/ people just don't know/ I need to be aware/ I don't want to raise my kids/ from a place of fear/ I'm kind of a bad ass/ I have actual OCD/I can't stop it/ I can't overcome it/ I take care of myself/ Am I ok?/Yeah I'm ok.../ I'm really proud of who I am"

"VIOLET"

OCD is/ more complex than anxiety/ the thought screams louder/ there is an element of shame/ they call it the Devil's Disease/ it's weird/ embarrassing/ ridiculous you know....but/ when you have children/ it's like your heart/ is walking outside your body/ you are not present/ because you are suffering/you can't control it/ you can't block it/ You can't risk it

OCD is/ lurking like a shadow/ always looking over your shoulder/ admitting the thought/ is the most potent thing/ to kill it:/ like let me tell you what/ my OCD/ said today/

your brain is trying/ it just learned the wrong way.

Awareness, knowledge/ Faith, prayer/ Trust your instincts/ if you feel something is wrong/

It could be OCD/
And you are not alone

APPENDIX F

APPROVAL LETTER

Approval Notice
Initial Review (Response To Modifications)

February 15, 2019

Amanda Knepper, MSW
Jane Addams College of Social Work
Phone: (630) 649-9419

RE: **Protocol # 2018-1613**
       **"Help-Seeking Among Women with Postpartum OCD: A Phenomenological
       Exploration"**

Dear Ms. Knepper:

Your Initial Review (Response To Modifications) was reviewed and approved by the Expedited
review process on February 14, 2019. You may now begin your research

Please note the following information about your approved research protocol:

> **Please note that as per the revised Federal Regulations (2018 Common Rule) and OPRS
> policies your research no longer requires a Continuing Review; therefore, the approved
> documents are stamped only with an approval date. Although your research no longer
> requires a Continuing Review, you will receive annual reminder notices regarding your
> investigator responsibilities (i.e., submission of amendments, final reports, and prompt
> reports), and will be asked to complete an Institutional Status Report which will be sent
> to you via email every 3 years. If you fail to submit an Institutional Status Report, your
> research study will be administratively closed by the IRB. For more information
> regarding Continuing Review and Administrative Closure of Research visit:
> http://research.uic.edu/node/735.**

Protocol Approval Period: February 14, 2019
Approved Subject Enrollment #:   10
Additional Determinations for Research Involving Minors: These determinations have not
been made for this study since it has not been approved for enrollment of minors.
Performance Sites: UIC
Sponsor: None
Research Protocol(s):

   a)   Help-Seeking among Women with Postpartum OCD: A Phenomenological Exploration
        (IR Application); 02/14/2019
Recruitment Material(s):

APPENDIX F (continued)

    a) Flyer (Postpartum OCD); Version 1; 12/16/2018
    b) Initial Contact Telephone/Email Script (Postpartum OCD); Version 2; 02/14/2019
    c) Participant Screening Sheet (Postpartum OCD); Version 2; 02/14/2019

Informed Consent(s):

    a) Consent (Postpartum OCD); Version 3; 02/14/2019

    b) A waiver of documentation of consent has been granted under 45 CFR 46.117(c)(2) for recruitment screening purposes only; minimal risk; written consent will be obtained at enrollment.

Your research meets the criteria for expedited review as defined in 45 CFR 46.110(b)(1) under the following specific category(ies):

(6) Collection of data from voice, video, digital, or image recordings made for research purposes., **(7)** Research on individual or group characteristics or behavior (including but not limited to research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

Please note the Review History of this submission:

Receipt Date	Submission Type	Review Process	Review Date	Review Action
12/19/2018	Initial Review	Expedited	12/20/2018	Modifications Required
01/24/2019	Response To Modifications	Expedited	02/14/2019	Approved

Please remember to:

→ Use your **research protocol number** (2018-1613) on any documents or correspondence with the IRB concerning your research protocol.

→ Review and comply with all requirements on the guidance,
    "UIC Investigator Responsibilities, Protection of Human Research Subjects"
        (http://research.uic.edu/irb/investigators-research-staff/investigator-responsibilities).

Please note that the UIC IRB has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

Please be aware that if the scope of work in the grant/project changes, the protocol must be amended and approved by the UIC IRB before the initiation of the change.

APPENDIX F (continued)

We wish you the best as you conduct your research. If you have any questions or need further help, please contact OPRS at (312) 996-1711 or me at (312) 996-9299. Please send any correspondence about this protocol to OPRS at 203 AOB, M/C 672.

Sincerely,

Allison A. Brown, PhD
IRB Coordinator, IRB # 2
Office for the Protection of Research Subjects

Enclosure(s): Approved and stamped documents are available via OPRSLive.

1. **UIC Investigator Responsibilities, Protection of Human Research Subjects**
2. **Informed Consent Document(s):**
   a) Consent (Postpartum OCD); Version 3; 02/14/2019
3. **Recruiting Material(s):**
   a) Flyer (Postpartum OCD); Version 1 12/16/2018
   b) Initial Contact Telephone/Email Script (Postpartum OCD); Version 2; 02/14/2019
   c) Participant Screening Sheet (Postpartum OCD); Version 2 02/14/2019

cc: Creasie Hairston, Jane Addams College of Social Work, M/C 309
        Amy Watson (Faculty Sponsor), Jane Addams College of Social Work, M/C 309

APPENDIX G

EMOTIONAL DISTRESS PROTOCOL

Protocol for Emotional Distress and/or Disclosure of Suicidal Ideation

Help-Seeking Among Women with Postpartum OCD: A Phenomenological Exploration

Principal Investigator: Amanda Knepper, MSW, LCSW
Faculty Sponsor: Chang-ming Hsieh

This research involves interviews with women about their experiences with postpartum Obsessive Compulsive Disorder (OCD). The interview will cover topics of a sensitive nature. As the lived experience of OCD may be emotionally difficult to reflect upon and discuss, it is possible that participants could experience some degree of emotional distress while reflecting on their experiences with OCD during the interview.

It is not expected that participants will disclose suicidal thoughts or plans while discussing their experiences with postpartum OCD, and the interview questions do not ask about thoughts of suicide. However, a process for responding to verbally expressed thoughts of suicide, or a plan to commit suicide, is detailed below. The consent form also clearly states the conditions in which the researcher may need to break confidentiality, including the disclosure of child or elder abuse, or the intention to harm oneself or another person.

The principal investigator, who is a Licensed Clinical Social Worker (LCSW), will personally conduct all interviews. The investigator is trained in suicide assessment and crisis support. The following protocol details the steps that will be taken in the event that the participant experiences emotional distress and/or verbalizes thoughts of suicide or expresses a plan to commit suicide.

Steps to Follow if Participant Experiences Emotional Distress

If a participant verbally expresses that they are feeling emotionally distressed, or expresses symptoms of emotional distress (e.g. crying, extended periods of silence while appearing emotionally upset, etc.) the following distress protocol will be utilized.

A) Ask participant if they would like to pause or terminate the interview

    a. If YES: Stop interview immediately. Go to Item B.
    b. If NO: Continue the interview, reminding the participant that they may terminate or pause the interview at any time.

B) If participant chooses to stop or pause interview, ask if they would like to debrief about their experience.
    a. If YES: Listen and provide emotional support as appropriate to the situation. If participant is not currently in mental health treatment, offer to provide referrals to psychological services and community support resources (i.e. support groups). Assess for risk of harm if indicated (e.g. participant discloses thoughts of self-harm). If appropriate,

resume semi-structured interview if/when participant verbalizes they would like to do so. Remind participant that they may stop at any time.

b. If NO: If participant is currently in mental health treatment, suggest that they discuss these feelings with their provider. If participant is not currently in mental health treatment, offer to provide referrals to psychological services and community support resources (i.e. support groups). Assess for risk of harm if indicated. If appropriate, resume semi-structured interview if/when participant verbalizes they would like to do so. Remind participant that they may stop at any time.

Steps to Follow when Suicidal Ideation has been Verbalized

A) Ask participant if they are experiencing these thoughts and feelings NOW?

a. If NO: Stop questions here. Offer referrals and/or linkage to support resources if indicated. Continue interview if/when participate verbalizes a desire to do so.
b. If YES: Move to Item B.

B) Ask participant if they are currently in treatment?

a. If NO: Ask if they would contact crisis services if they felt they were not able to stop themselves from causing harm to themselves. In this context, "Crisis services" refer to: Hospital-based behavioral health center that provides immediate crisis intervention, assessment, and referral via appointment, walk-in, or phone call; or B) A 24-7 crisis hotline, such as The National Suicide Prevention Lifeline which links callers with a trained mental health crisis counselor at a local crisis center. Document name of the crisis service the participant says that they would contact (if provided). Move to Question 1. If participant indicates that they would call but do not know who to contact, provide referral sheet for crisis services convenient to them, and receive verbal assurance that they will contact if they feel they are at imminent risk of harming themselves. Move to Question 1. If participant indicates that they are unwilling to talk with a provider or crisis services, move to Question 1.
b. If YES: Move to Item C.

C) Ask participant if they have discussed their thoughts/feelings with their treatment provider?

a. If NO: If the participant has not spoken to their provider about their current feelings/thoughts and indicates that they are not willing to do so, ask if the participant would be willing to talk to a crisis service if they were not willing to talk with their provider. If YES, ask for and document the name of the crisis service identified. Move to Question 1.
B. If YES: If the participant indicates they have spoken to their treatment provider about their current thoughts/feelings, ask for and document name of provider. Receive verbal assurance that they would contact their provider or a crisis service if they felt that they were at imminent risk of harming themselves. Stop questions here.

APPENDIX G (continued)

QUESTION 1: Ask when a person is not currently in treatment, or not willing to discuss their feelings/thoughts with a treatment provider or crisis services.
Before asking, educate the participant that the researcher is required to consult with a professional treatment provider or crisis service when anyone reports **a specific and serious intent to commit suicide, or has a specific plan to commit suicide**. Remind the participant that the consent form provides information on this as well.

QUESTION 1: Ask participant if they have a specific plan to commit suicide.
> a. If NO: Offer to provide referral or direct linkage with a local crisis service. Encourage that they speak about their thoughts/feelings with their current provider, or a crisis service. Provide referral sheet for crisis services.

> b. If YES: Ask about the plan, but do not probe if they refuse to disclose. Ask that the participant contact their provider or call crisis services NOW. If they refuse to make the contact, offer to do so on their behalf. If participant still refuses, remind them again that you are now obligated to consult with a treatment provider or crisis service, as described in the consent form. If the participant continues to refuse, the researcher will contact the individual's treatment provider. If the treatment provider does not answer, or the participant does not have a treatment provider, the researcher will contact the nearest hospital-based crisis services center and disclose that the participant has disclosed intent and/or a specific plan to commit suicide.
>   - The participant or researcher will contact treatment provider or crisis service as described above.
>   - Proceed according to instructions given by treatment provider or crisis counselor.
>   - The outcome of the call will be documented.
>   - A detailed description of protocol that was followed will be written up.
>   - The UIC IRB and the faculty sponsor will be promptly informed of the incident